Witness Name: GRO-B
Statement No.: WITN0450001
Exhibits: **WITN0450-002**
Dated: 05/07/2019

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 20/12/2018.

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

Section 1. Introduction

1. My name is GRO-B and I was born on GRO-B. My date of birth and address are known to the Inquiry. I live GRO-B with my husband and my dog. I have an adult daughter who has left home and I have had special guardianship of my grand daughter since 2008. I was formerly a beauty therapist and retail manager but have recently retired.
2. I intend to speak about the circumstances of my infection with hepatitis C (HCV), the nature of my illness, the treatment that I received, how it has affected me and my family, and my treatment at the hands of government bodies and various medical professionals.
3. I would like my witness statement to be anonymous to protect the identity of my family and myself from the stigma of this infection.

Section 2. How Infected

4. In May 1988 I presented at my local GP surgery with symptoms of lethargy, bleeding from my gums, being unable to stand for long periods of time, and unexplainable bruises. The first GP I saw, Dr GRO-B sent me home and told me that I was a "hypochondriac". The inquiry team has explained the right of reply for medical professionals to me.

5. On May 12 1988 GRO-B), I saw another GP, Dr GRO-B who gave a second opinion and diagnosed me with acute Myeloid Leukaemia. My daughter was GRO-B old at this time. I was rushed straight to Addenbrooks hospital where blood tests revealed my low platelet count. I had a bone marrow biopsy and subsequently went into chemotherapy. I received my first blood transfusion that night in hospital.

6. Treatment started in earnest that weekend. My first course of chemotherapy lasted ten days and when I had slightly recovered I immediately underwent another eight-day course. The chemotherapy treatment involved multiple and frequent blood transfusions.

7. The hospital tested my brother for suitability as a potential bone marrow donor. Fortunately, he was a match and I proceeded with the bone marrow transplant despite knowing the horrendous effects it would have on me, rather than simply hope that my cancer would remain in remission. I didn't want to live my life and bring up my daughter with this disease hanging over my head.

8. My medical history concerning blood transfusions is extensive. Throughout the period of interventions for my leukaemia the staff would regularly take my blood in the morning to examine whether my blood count had risen. They would then later replenish my blood supply via a blood transfusion.

9. For a time I felt like a vampire. In the morning I would feel so low that I could barely stand up and then following a transfusion I would generally feel energised and prepared for the day.

10. I remember being told by my mother that I was attached to a blood bag every day that she went in to visit me. It is impossible for me to recall the exact number of transfusions I received, but given the 31 weeks I spent in

hospital (7 in isolation, 24 in recovery), the number could be anywhere from 30-50 or even more.

11. The nature of hepatitis C means it is impossible to designate an individual transfusion as the source of my infection but it must have been one of the procedures during this period of time.

12. I remain unsure of the reasoning or justification behind many of the transfusions I received; I simply placed my trust in the NHS and the doctors who were attempting to help me. I know that many of the transfusions were necessary as part of my treatment, but I am unconvinced that all of them were, considering how my infection risk would have increased with each cumulative transfusion. It was only in December 1989 that I stopped receiving regular transfusions.

13. I found out purely by chance that I had become infected with hepatitis C. In May 1993, while in hospital for an unrelated surgery, a junior doctor looked at my chart and said: "*I see you have hepatitis C, how do you manage this?*"

14. I was completely gobsmacked. I was aware of hepatitis A and B, but I had never even heard of hepatitis C and had absolutely no idea what it was or what having the disease would mean for my health.

15. When I was diagnosed my concerns about the infection were put aside as the medical team pushed through and focused on my unrelated surgery. I made an appointment to see my GP and ask about hepatitis C.

16. My GP had no idea about my infection; it was not in his notes and nobody at the hospital where they had diagnosed me with hepatitis C had sought to pass on any records or get in touch with my doctor or me. My GP couldn't tell me what hepatitis C was other than that it pertained to the liver.

17. When I was belatedly informed of my infection with hepatitis C, I was not provided with any information on how to go about managing the condition. The limited information I was provided regarding how to reduce the infection risk for my family and friends turned out to be inadequate or incorrect.

18. Once my GP had confirmed my diagnosis I was referred to the hepatologist, Dr Alexander at Addenbrooks hospital in November 1993. Dr Alexander told me that hepatitis C was a new form of the disease and that the medical profession was still learning about at the time.

19. I was told that it was a mild form of hepatitis and that while I would have it for life I wouldn't know that I was infected due to the lack of symptoms and side effects.

20. At the time I was diagnosed, I believe the medical professionals responsible for my health should have provided me with the most up to date knowledge on the subject that was available at the time. In hindsight given my understanding now, I doubt that those professionals were even aware of the latest information concerning hepatitis C at the time.

21. While this should not absolve those doctors of their responsibility or forgive the astonishing lack of bedside manner I was shown, it would indicate that the ignorance and misinformation amongst doctors was a systemic issue and not an individual one.

22. I am appalled that my consultants would have known about my infection for so long without considering informing me. When I did finally learn about my hepatitis C it was in a dismissively offhand manner by a junior doctor who I did not even know, and who simply read my test results off a chart in a crowded ward where other patients would inevitably overhear this private conversation.

23. When I was informed of my infection, I was told that the disease could be transmitted through any bodily fluids. I was to keep a separate towel, use individual utensils, and be extremely careful with anything that I could get my blood or saliva on.

24. This information naturally led me to make drastic changes to my everyday life for fear of infecting my family and friends. My quality of life decreased overnight.

Section 3. Other Infections

25. I do not believe that I ever received any infection other than hepatitis C as a result of being given infected blood or blood products.

Section 4. Consent

26. I received a large amount of blood transfusions between May 1988 and November 1989. I do not believe that all instances of this treatment were given with my informed consent considering how little I knew about what those transfusions were for.

27. When I received those treatments the information I was provided both as to the relevant risks involved in the treatment, and as to what the medical justification for those treatments were, was entirely inadequate.

28. I believe that the blood tests I was receiving from oncology in the years following my initial infection were conducted without my consent. The consent I gave was specifically for blood tests to follow up my leukaemia yet Addenbrooks hospital were clearly looking for traces of hepatitis C in my blood without telling me that they were doing so.

29. I believe that I was tested for the purposes of research. I was informed that because I was Addenbrooks' first bone marrow transplant recipient, my case would be used as a research study. This research was not related to hepatitis C.

Section 5. Impact

Mental and Physical effects

30. The effects of being infected have profoundly influenced my lifestyle over the past thirty years. I was exhausted, absolutely knackered by things that used to be everyday activities. I don't sleep very well anyway, but whenever my hepatitis symptoms were at their worst I could not sleep at all.

31. I suffered from brain fog, which affected both my coordination and my cognition and could make basic tasks a challenge. Most of the time when I was awake I would be overwhelmingly fatigued and this combined with my lack of ability to sleep often left me in a bad way.

32. I experienced major mood swings that would leave me crying and highly upset. If a setback or anything slightly negative happened I would have no resilience whatsoever and would be hit really hard.

33. If I ever displayed flu-like symptoms I would have to head straight to hospital because it was a sign of further infection. Being so vulnerable to infection while raising a young daughter was a difficult challenge. I would cross the road if I saw someone coughing and would wear a facemask into Addenbrooks hospital or similar environments to prevent infection.

34. The stress that I experienced from the hepatitis C symptoms and the struggle of continuing to work when I felt so awful also meant that I developed alopecia in the mid 1990s.

35. I've always suffered from migraines and itchy skin and these issues were exaggerated by my hepatitis C symptoms. Joint pain has also been a long-term issue for me, which has now developed into osteo-arthritis.

36. Following the bone marrow transplant I received from my brother I unfortunately developed cirrhosis in my liver. This was hard for me to take and very upsetting for my brother at the time.

37. Looking back now I can say that all of these mental and physical effects can be attributed in whole or in part to my infection with hepatitis C at the hands of the NHS.

Impact on my private, family, or social life

38. Only my close family and a small circle of close friends were aware of my infection throughout the extended period when I was dealing with its symptoms and the side effects of treatments.

39. I don't believe that I was significantly stopped from doing specific things that I wanted in my life. However, it was difficult not being able to tell

people around me what I was actually going through or the true reasons why I couldn't do certain things.

40. If I was offered a drink when out with the girls I would have to say, *"I don't drink"* rather than address what my actual circumstances were. Often it was easier to avoid the truth in social situations like this but this is an uncomfortable thing to continually do.

41. The effects of my infection meant that my daughter would sometimes dread getting home from school. If she saw that the curtains were closed when she arrived home then she knew I would be asleep on the settee and wouldn't be able to look after her as well as I would have liked.

42. My daughter went off the rails GRO-B GRO-B GRO-B I know now that her choices were nothing to do with me, but the effects of my hepatitis C meant that at the time I felt absolutely responsible for the situation.

43. Married life has been difficult at times but GRO-B was and continues to be possibly the best husband ever. He has always been there for me, supportive and understanding of my needs.

44. When we wanted a baby of our own my hepatitis C was an obstacle as it could be transmitted if I went through IVF. All of the setbacks and changes to our lifestyle ensured a confusing and challenging time for us both.

45. When my mum found out the NHS had infected me she was furious. My brother was absolutely devastated; we had just completed the bone marrow transplant process and then finding out about my hepatitis C made him think he was going to lose his sister. The outcome of my Leukaemia and bone marrow transplant had been so positive and this was taken away by the news of my hepatitis C infection.

46. My daughter's former partner was aware that I had hepatitis C and he took advantage of that fact to report it to social services when there was a dispute over special custody of my grandchild (the partner's daughter).

47. He knew that social services would assume that I had contracted my infection through negative lifestyle choices and not at the hands of the NHS and sought to maliciously use that stigma against me.

48. Unfortunately he partially succeeded as I faced a constant battle to provide evidence and convince social services that my infection had occurred through no fault of my own. This occurred because of the distinct lack of publicity or public awareness for a long time of the possibility of contracting hepatitis C through infection and the NHS' role in that process.

Impact on my education, work life, and finances

49. My family has always owned or been involved in retail businesses and consequently I've been in work since around the age of eight. Hard work has always been an important part of my life and it is frustrating that hepatitis C has prevented me from achieving some of the career goals that I otherwise might have.

50. I am a fully qualified beauty therapist and that is a career I would have loved to follow further had I been able to. Unfortunately when I found out about my infection I had to give up my work and leave the industry entirely because the risk and thought of infecting anyone else was too horrific.

51. From 1992 I worked in a retail manager role for the business GRO-B I enjoyed my work there, having plenty of responsibility and interacting with customers but I eventually had to give up this work due to the severe exhaustion I was suffering from.

52. I wanted to be an area manager in retail. I liked the paperwork and the training side as well as the potential earning capability. Hepatitis C deprived me of that opportunity and many others during what should have been the prime earning years of my life. I used to find it soul destroying if I was forced to call in sick because of my infection.

53. My husband and I have never been wealthy and we never will be. We both work and my husband now has his own business. I am T cell depleted so my immune system is such that the slightest contact with a cold could lead

to pneumonia for me; this presents a constant challenge in work environments.

54. I can't get life insurance due to hepatitis C. I have tried over the years without success. Eventually some said that they would insure me but only with extortionate premiums that my husband and I could never afford on our incomes. If I travelled I generally haven't told the insurer of my infection.

55. When GRO-B and I wanted to apply for a mortgage I was refused because of my infection so all the paperwork had to be exclusively in GRO-Bs name with an associated inferior interest rate.

Section 6. Treatment/Care/Support

56. The treatment and care that I needed or received had negative effects on my life beyond that of my infection itself. In this section I will discuss both the way in which I was treated medically and also the inadequate nature of other support was offered to me at the time.

57. Prior to an unrelated operation in 1993 at Addenbrooks hospital I asked whether my blood was OK, given that I was aware of a rise in my enzyme levels. I was incorrectly told: *"Your blood is fine"* by the unknown doctor on duty at the ward.

58. Dr Alexander further told me in 1993 that hepatitis C was a mild form of the disease that I would never suffer any ill effects from. It was apparently *"Absolutely nothing to worry about."*

59. For five years from when I was diagnosed with hepatitis C I was required to visit the oncology department each week for blood tests. I ended up questioning why I had to go to Addenbrooks hospital every year, which resulted in the yearly blood tests being conducted by my GP.

60. Because I was never told of anything untoward or that there was any risk that I had previously contracted an infection, life at this point was otherwise beginning to return to normality.

61. Following one of these blood tests I was informed via letter that there had been an unusual rise for one of the enzymes in my blood. I returned to the hospital for further testing and this is where I was belatedly informed of my infection (see paragraph 13 above for details of how I was treated there).

62. Throughout the period I was being tested I was only aware that they were following up on my leukaemia treatment and not that they were searching for signs of the hepatitis C that I had been infected with. This reflects a general pattern of a lack of appropriate communication from the NHS about what had occurred and what was currently going on with my transfusion-transmitted disease.

63. In between hepatology engagements I also had an appointment that recognised and celebrated that five years had passed since my leukaemia was successfully treated.

64. I felt like this was a real achievement at the time but that feeling was undermined when I was told by a Leukaemia consultant that the NHS infecting me with hepatitis C was *"Just one of those things"* when he was on his way out of the door.

65. This is just one example of the callous, dismissive or indifferent responses I have received from medical and other professionals when they have been informed of my infection.

66. In late 1999 I received a second biopsy in addition to a variety of different blood tests. I was told that there were new testing methods (but not what the tests were) and that the doctors wanted to see how far the disease was progressing within my system.

67. I got a phone call at home late one evening from hepatology; six tests had returned fine but the seventh had come back and it wasn't good news so I had to return to the hospital. A few days later I went in with GRO-B to see Dr Alexander and two doctors from hepatology.

68. The test results had shown significant damage to my liver. A doctor who was unknown to me said: *"Don't plan any more parties."* I thought that I was going to die within the next two years. They did not give me any more information beyond this at the time.

69. I did not ask further questions because I was in shock and absolutely devastated, as was my husband. I came home and tried to digest what we'd heard. I didn't tell my daughter, I told my mum instead.

70. I wanted my daughter to carry on as if nothing was wrong. I wanted her to be able to enjoy her life and not worry about me. She was my one and only daughter and I didn't want to change the relationship that we had. Over the two years that I expected to be my last I was never once told that my prognosis or my condition had improved.

71. I was informed that my normal regime of yearly blood tests would continue. In the meantime and given the lack of information being provided to me I decided to do my own research into what was going on. Part of my coping mechanisms is that I always have to know as much as possible about what is going on. Being infected with hepatitis C and thinking that I may not have long to live threw me into turmoil and I wasn't getting any information or support from anybody.

72. Research I read online estimated that there was a 74% chance that my hepatitis C would develop into either cirrhosis or cancer. No further information had been given to me following my biopsy so I was left in the dark about what exactly was wrong with me and why my prognosis was so dire.

73. I learned through my own research that all the symptoms I was having could be attributed to hepatitis C. In 2004 I received another liver biopsy. I was informed that I had moderate fibrosis of the liver. No change of prognosis was communicated to me.

74. There was no offer of counselling, psychological help or any other form of support. The only time counselling has been mentioned to me was as part of the 'Lookback' program and apparently that counselling was not intended for me.

75. At some point I was informed about the Ribavirin/Interferon treatment and also the horrific the side effects that it involved. My focus at that stage was on quality of life and that led me to decide not to participate in the treatment regime.

76. In late 2016 I received word from the hepatology department that there was a new 'Harvoni' treatment that was now available. The treatment began in June 2017 and consisted of an 8 week program. Harvoni side effects could include tiredness, sickness and body aches. I had to swallow a large tablet everyday with breakfast and at the conclusion of the course I had to have blood tests and a fibrous scan.

77. My diary for that time records that I felt very tired and sick and was nervous before taking the pill and woozy afterwards. This diary is in deep storage but could be made available to assist the inquiry at their request. I experienced dizziness, was lethargic and my body felt so heavy that I felt like I could have fallen asleep on a washing line. About four hours after taking the tablet I would fall asleep and feel better but being sick or asleep for so much of time everyday affected my life significantly.

78. Later in 2017 I went for my final blood test following the Harvoni treatment. A few days later I received a letter from hepatology stating that there was no trace of hepatitis C in my blood.

79. I felt fantastic. There was an overwhelming feeling of relief and a weight off my shoulders and my life. My husband cried and for the first time it felt like it was over.

80. For so long I'd been so ill and had to deal with the stigma of hepatitis C; every time I went to see the doctor there would always be in your face information about needles and hepatitis C.

81. Being infected has included smaller frustrations that combined to make my life worse. For example I underwent an unrelated surgical procedure and informed the medical professionals that I was hepatitis C positive (no-one else had mentioned it or even noticed). As a result, despite my original early morning appointment I had to wait without eating or drinking until the final slot to receive surgery because the hospital was apparently unable to adequately sterilise their equipment.

82. I continually faced difficulty getting other treatments. I received a cataract operation as a consequence of radiation therapy side effects. The medical

staff were able to complete the operation on one of my eyes (in 1990), but they refused to attempt the second (late 1993), because of my hepatitis C.

83. I was told at the time that they couldn't sterilise their equipment sufficiently to prevent my operation being an infection risk for others. When I asked at a later date, their reason had changed to be the swollen blood vessels behind my eyes (possible radiation side effect), which made the operation too dangerous.

84. My dentist was very good about my infection. Another side effect of radiation was that my teeth began crumbling which has required extensive dental work. Recently I had to have multiple extractions and the dentist asked for a certificate to demonstrate that I was now clear of hepatitis C.

85. I would like to commend the excellent Dr Cornish for the sessions I had with him. I was being so strong in dealing with the disease in my regular life that I needed a space where I could explode and to let out all of my emotions. I have been made aware of the counselling support helpline offered by the British Red Cross as part of the inquiry.

86. I was so exasperated by the lack of information being provided to me that I sought legal advice. Adams Harrison solicitors had represented me through previous divorce proceedings; so I instructed them to contact the NHS and find out how a blood transfusion had given me hepatitis C.

87. The NHS replied to a letter that these solicitors sent on my behalf. This reply is the only document I ever received from the NHS regarding their responsibility for my infection. The NHS' letter denied their culpability in the circumstances surrounding my infection and dismissively suggested that medical procedures always involve risk.

88. The document is largely reproduced at paragraphs 89-91 below (it is attached as exhibit 002). I believe this letter represents the bare minimum that the NHS thought they could get away with when communicating to victims. The NHS have been callous and dismissive, tried to shift the blame towards victims, and never accepted responsibility or offered a full apology to victims like myself. The letter included the following text (emphasis added):

89. *"Ministers have consistently stated, for example in the adjournment debates in the House of Commons in July and December 1995, that the Government has great sympathy with those patients who may have become infected with hepatitis C through blood transfusions or blood products. However* ***medical procedures rarely come without risk and these are not always fully known or capable of being guarded against at the time.*** *These patients received the best treatment available in the light of medical knowledge at that time."*

90. *"The* ***Government does not accept that there has been negligence and they have no plans to make payments to such patients****. On the more general issue of compensation, the Government has never accepted the case for a no fault scheme of compensation for medical accidents. It is unfair to others and still requires proof of causation which is often difficult to establish. Each individual case where a medical accident has occurred is a personal tragedy for both the individual and their family. If the NHS is proved negligent in court, it accepts its liability to pay damages."*

91. *"It is the Government's view that the most effective use of resources is to seek to improve the understanding, management and treatment of the condition. Only in this way can the impact of the disease on individual patients and their families be minimised."*

Section 7. Financial Assistance

92. I received a Stage 1 payment of £20,000 in 1994. I found out about Skipton online when I was viewing conversations in a haemophiliac society chat group. The application process was relatively straightforward; I filled out the form and sent it to hepatology for them to complete.

93. EIBSS took over the scheme and is now paying me £18,000 a year; £1500 every month plus a £500 winter fuel allowance.

94. I received a letter saying this payment relief was in no way compensation. I feel that even now, nobody is willing to take the blame whereas it is clear that somebody is to blame and should be held accountable.

95. For a long time I felt guilty for asking questions or seeking to find out more. The burden of finding out more and informing me should have always been upon the NHS because they are responsible for my infection.

Section 8. Other Issues

96. Overall I am angry, bitter and resentful about my infection and the way I was treated following it. If I knew then what I know now I would have sat there in the hospital until I got some answers.

97. You put all your trust and your faith into the health service and the doctors and you don't question their advice. This inquiry has been a long time coming and should have occurred years ago. It's frustrating and we need closure.

98. I am fortunate enough to have eventually been treated but they have still let me and everyone else down; effectively sweeping the issue under the carpet and telling me not to ask any questions.

99. I want this all to be over. I need the people and institutions responsible to say; yes we did this, yes we did cover it up, yes we have let thousands of people down, and no we won't let this happen again.

Statement of Truth

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

Signed GRO-B

Dated 5/07/19