Witness Name: GRO-B
Statement No: WITN0193001
Exhibits: **WITN0193002 - 003**
Dated: 14th March 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 4th March 2019.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1960. I live with GRO- my partner of 26 years in our home in GRO-B I intend to speak about my infection with Hepatitis C. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it has had on GRO-B and I, and our lives together.

2. I confirm that I am not legally represented and that I am content for the Inquiry team to assist me with my statement.

Section 2. How Infected

3. In February 1974, I was suffering with suspected appendicitis whilst I was living at home with my parents and siblings. I was 14 years old.

4. On 23rd February, I was admitted into GRO-B Hospital for an appendectomy. However, it transpired that I had peritonitis, with a double abscess on my appendix. These burst prior to my surgery, requiring an emergency operation. I was admitted into the ICU for four days and recall having a saline drip in one arm, as I was unable to administer food and water, and a blood transfusion in the other.

5. My parents were told 'don't be surprised if he comes back in six months, because his bowel is damaged'. They were right; I had to have a laparotomy and bowel excision. Once again, I was admitted into ICU and I recall having further blood transfusions. In total, I spent around four to four-and-a-half weeks in hospital.

6. As I was around 14 years old at the time, the clinicians spoke to my parents about the treatment I needed. However, I do not think they were given any information or advice about the risk of infection associated with blood transfusions.

7. As a consequence of the blood transfusions I received, I contracted Hepatitis C.

8. I did not find out I had Hepatitis C until April or May of 2006, some 32 years after being infected, when I went with my partner to give blood. She had given a few times before and convinced me to go with her.

9. Some time after the donation, I received a letter in the post, informing me that my blood couldn't be used because it was infected. It further informed me that my GP would be informed GRO-B also received a letter

at this time saying that because I had Hepatitis, she could no longer be a blood donor.

10 GRO-B has told me that she went through a lot anxiety at the time as she thought she could have been responsible for my infection, due to the behaviour of someone she was previously associated with. Though she has never been tested, we know she does not have Hepatitis, as the Blood Service did not tell her she was infected at the time they told me.

11. At the time, I was told the only way I could infect someone else was if their blood came into contact with my own. I was not given any advice on the long-term repercussions of being infected. The only conclusion I was able to draw was that I had got it when I had my operations, as I have never used intravenous drugs, nor do I have any piercings or tattoos.

12. I was diagnosed following a liver biopsy, which felt like I was being stabbed with a garden fork. The results were not communicated to me clearly at all. Further, the doctor giving me my results, Dr Gells, had told me that the treatment for Hepatitis would cause me to have flu-like symptoms, which I did not want at a time when I felt well. Although I queried this at the time, Dr Gells was very vague. He treated me as if I were an alcoholic with cirrhosis, rather than someone who contracted Hepatitis from a transfusion. He also told me that he thought I was ineligible for the Skipton Fund, causing further confusion. I made a formal complaint to the Biopsy Clinic at Addenbrooke's, which I exhibit as **WITN0193002.**

Section 3. Other Infections

13. I do not believe I have been infected with anything other than hepatitis C as a result of my blood transfusion.

Section 4. Consent

14. Given that I was a child at the time of my infection, my parents consented to my surgery on my behalf. I was in the ICU much of the time, and as such, was unaware of what was going on.

15. However, I do not believe I have ever been treated or tested without my knowledge or consent. Nor do I believe I have been tested for the purposes of research.

Section 5. Impact

16. When I found out about my infection, my first thought was 'why me?' and 'how has this happened?' I didn't know what would happen to me, nor if the illness would kill me.

17. I am always tired. I get around eight hours sleep each night but wake up every morning just as tired. Even when I was in my early twenties when I would go out drinking and playing sports I would not be able to last as long as my peers. As the years went on, I started to slow down much more early than I should have done. When I stop and sit down, I do nod off easily, we always attributed it to working hard and running a house but maybe in hindsight, this was due to the Hepatitis Infection and the subsequent use of Interferon.

18. Our social life has definitely taken a hit. We don't go out very often but when we do, we are never home later than 10pm, that's a late night for us.

19. In January 2007, I was referred to Cambridge Hepatobiliary Service, but did not begin treatment for Hepatitis until July 2008, at Addenbrooke's.

20. My first treatment was a six month course of Interferon, which I injected once a week on a Friday night and took in conjunction with Ribavirin tablets.

21. The Interferon injections were hell. They put a strain on our relationship and GRO-B says I was awful to live with when I was on Interferon; we came close to separating several times.

22. After injecting, I would feel cold and would shiver, so would go to bed, but would have cold sweats at the same time. It knocked the life out of me and I would feel awful all weekend after injecting and my fingers and toes would go numb. I felt low and depressed and lacked any motivation to do anything.

23. I do occasionally forget things, which can be frustrating for GRO-B as I don't always remember saying something, but she is very understanding of this.

24. After the first course of Interferon, we moved house. It was 18 months before I heard anything again, and I can only assume my address was lost somewhere along the way. Then, I received a letter informing that the treatment hadn't worked and that I would need to begin a second round of Interferon, which would last for a year. Again, I took this with Ribavirin.

25. I would go for regular six-monthly check ups with Sister GRO-B GRO-B at GRO-B These appointments are now every 12 months, with the last one in October 2018 and the next scheduled for October 2019.

26. GRO-B has said that if, at my next appointment, everything is as it should be, then I will be discharged from their service. My liver is currently functioning normally and I have no cirrhosis, despite having some liver scarring. GRO-B thinks it's concerning that I am being

discharged, as we don't know how the infection will affect me in the future. For me, though, I just see every day as a bonus.

27. I drink very rarely and though I used to smoke, I stopped in 2014 when I was diagnosed with cancer in my neck. I think this has helped to prevent any further damage to my liver.

28. I had to have five of my teeth removed prior to receiving chemotherapy, and was not treated any differently by my dentist or anyone at the surgery. My dentist knows I have Hepatitis and has no issues treating me.

29. I never faced any discrimination at Addenbrooke's, most of the staff who treated me were and still are excellent.

30. I was 14 or 15 when I was infected, and left school at 16, unrelated to my infection. I don't recall whether my education was compromised following my operations, but do remember having bellyache, which I attributed to my bowel resection.

31. I have never taken time off work as a result of being infected, or during my Interferon treatment. I have worked consistently since I was 16, only taking time off when I was undergoing chemotherapy and radiotherapy for the aforementioned cancer. I am self-employed and as such, couldn't afford to take the time off work. Consequently, Hepatitis has not had a financial impact on my life. I have always just pushed on.

Section 6. Treatment/Care/Support

32. I do not believe I have faced any difficulties receiving treatment, care and support in consequence of being infected with Hepatitis C.

33. Counselling or psychological support has never been made available to my partner or me in consequence of being infected.

Section 7. Financial Assistance

34. I found out about the Skipton Fund entirely by accident while I was waiting to see my liver specialist at Addenbrooke's. Another patient there told me that I should contact the Skipton Fund for compensation. I told him I wasn't after money, and that I would rather have had my health, than any money.

35. My initial application for the ex gratia sum was in October 2007, but it was refused, due to lack of supporting confirmation that I received NHS blood or blood products during peritonitis and bowel section operations in 1974. My GP had requested my medical records on my behalf, though was told that they were destroyed. This hindered my Skipton Fund application greatly.

36. I appealed the decision after speaking to my consultant, Dr Ninkovic. She wrote to the Scheme Administrator, Nicholas Fish, at the Skipton Fund, confirming that it was 'highly likely that I did receive a blood transfusion as I required the excision of part of my bowel'. I exhibit this letter as **WITN0193003**.

37. The meeting of Skipton Fund's Independent Appeal Panel didn't take place until October 2008, despite me lodging my appeal in July that year. However, the Panel agreed that I was entitled to payments, and I received £20,000 on 4th November 2008.

38. In November 2016, I received a letter informing me that I qualified for Stage 1 payments, which amounted to £3,000 a year, plus £500 in winter fuel payments.

39. I am also in receipt of a low-income top-up scheme, which is around £130 a month, and is based on both mine and my partner's wages. This scheme is now under review, we've had to send both of our

wages and our council tax bill to re-apply for it. I don't know now whether or not we will still be eligible for these payments.

40. The money is useful, and we use it for things like occasional help around the house, and to pay for removal workers for when we last moved. It's a safety blanket for us.

41. It was through the Skipton Fund that I found out about the Inquiry.

Section 8. Other Issues

42. I do think that people higher up in the medical profession stereotype people. It was assumed that I was an alcoholic, without any other possibilities being considered.

43. My family, including my two sons do not know that I have hepatitis C and for this reason I wish for my statement to remain anonymous.

Statement of Truth

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

Signed GRO-B

Dated 14th March 2019