Witness Name: GRO-B
Statement No.: WITN0077001
Exhibits: **Nil**
Dated: 19th 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 28th January 2019.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1946 and my address is known to the Inquiry. I am retired and live with my husband. I have two children, long grown up and four grandchildren. I intend to speak about my experience contracting Hepatitis C from a blood transfusion in 1972. In particular, the nature of my illness, how the illness affected me, the treatment I received, and the impact it has had on my life and the lives of my family.

Section 2. How Infected

2. I gave birth to my son GRO-B on GRO-B 1972 at a GRO-B GRO-B where my husband GRO-B was based in the British Army at the time,

3. I had a very difficult birth, involving a forceps delivery and I had a very heavy post- partum (after the birth) bleed. My husband said there was blood on the ceiling, it was that bad. I was told that I needed to have a transfusion. I didn't want the blood at all; I actually remember wanting to pull the tube out of my arm. Looking back, I know it sounds strange but it was like I somehow knew that I shouldn't be having this blood. I was given two pints of blood. I received this blood transfusion somewhere between the birth of my son on GRO-B and the GRO-B 1972, when I was discharged.

4. I stayed in the hospital for about ten days. My skin was very yellow and I found out later that that I was jaundiced.

5. I had a daughter two years later when I still didn't know that I had been given bad blood. I carried on with normal life, which for me and my family entailed fairly frequent moves around Europe as my husband was posted from base to base. In the seventies we spent time in GRO-B and GRO-B In 1978 my husband was posted to GRO-B in GRO-B During these periods I was a civil servant Administrative Officer. I was fortunately able to get work wherever GRO-B was posted. I worked for 19 years before being made redundant. At that time, I was working at the Territorial Army Centre in GRO-B

6. I felt tired a lot of the time but I thought that this was because I had two young children running around. However, the tiredness never really felt like normal tiredness.

7. At some point after being posted to GRO-B my hands started to go black and swollen, I remember not being able to get my gloves off. My toes were also affected. It was very painful and it turned out that I had Raynauds disease. I spent a week at The John Radcliffe Hospital in Oxford. I was not informed how I may have got this disease. I know that it can come from being cold and that one of the symptoms of HCV

is feeling cold, hence the cold weather Skipton payments, though of course nobody knew that I had HCV at this time.

8. We went to live in GRO-B and at some point, my knees started to swell. I ended up in another British Military Hospital. I was not then diagnosed with HCV and was never subsequently told whether these issues were directly linked to HCV but I didn't have anything wrong with me before having my first child and the blood transfusion.

9. With the prospect of GRO-B retiring from the Army we bought a house in the GRO-B in around 1990 (my son was 18). My husband eventually stayed in and was commissioned but regardless of him being posted, over time we still had various houses in the GRO-B GRO-B When the disruption to the children's education became too much, they went to boarding schools in the UK. I continued to accompany GRO-B on his postings. In his latter years of service, GRO-B often went away for periods without me for instance to Iraq.

10. There were two occasions where strange things happened that the medical professionals were not able to explain. The first occasion was in 2002 when I began passing urine that was bright red like tomato ketchup. I also had a pain under my ribs and in my kidney and lower abdomen area. I felt very sick, especially in the early morning and had night sweats. I was sent to GRO-B hospital and was quickly put on antibiotics. I had a lot of pain in my ribs, kidney and lower abdomen, especially early in the morning. The antibiotics produced clear urine, however the blood returned as soon as I stopped taking them.

11. Sometime soon after this, I began vomiting up blood, a bucket full. I was sent to A&E at GRO-B and spent five days in Acute Admissions Investigations. Tests were done and I had a dye intravenously introduced to my system so that they could scan my

kidneys. I was told that I had a 'G1' or 'GI' bleed, I am not sure which but I understood this to mean gastrointestinal. They did tests on me but HCV was never considered. They didn't find anything like an ulcer.

12. After being discharged, I attended as an outpatient, the Cystocopy and Haematoma clinic where I was seen by Dr Rundle.

13. I recovered but I was still constantly tired. The GP decided to test my liver and soon after rang me asking me to come in to see her. I went in and she told me that I had HCV. She proceeded to ask me if I had ever had a blood transfusion. I told her I had.

14. She then told me that it was an Infectious disease and that I could have passed it on to other people. I was horrified because 30 years had gone by. I'd had my daughter two years after the transfusion. I recall her being absolutely covered in blood when she was born. Apart from that, I could have passed it to her during pregnancy or via breast feeding through chapped, sore nipples. By this time, my daughter was married and had children of her own. Thankfully, I did not breast feed my children, though I may have and for all anyone knew, I would not have been prevented. In other aspects, I could have passed on the infection just in the course of family and married life.

15. I said to the nurse that I could have passed it onto my daughter and she told me that it was very unlikely. I was given a small pocket sized book to help me to understand more about HCV. I read through it again and again, to understand about the virus. The book stated that there was a 5-7% chance of passing the virus onto your unborn child.

16. The nurse also gave me pages of documents printed from the internet about what HCV was, the symptoms, how it could be passed on, about the available drugs and treatments and their potential side effects. I still have these. I can provide them to the Inquiry if necessary.

Section 3. Other Infections

17. Other than HCV, I am not aware of contracting any other infection that can be definitively said to be as a result of the blood transfusion or the HCV, though I did get Reynauds disease and there was the passing of and vomiting blood that I have described elsewhere in this statement.

Section 4. Consent

18. I did not consent to the blood transfusion. I was not asked if I wanted the transfusion I was told that I had to have one and so I complied. I had just been through a traumatic birth. Had I been asked, I probably would have consented, but I wouldn't have consented to receiving contaminated blood.

Section 5. Impact

19. What really hurts me is the stigma attached to HCV and the way that people treat me and my own perceptions of what people may think, whether real or not.

20. I had long left the Civil Service and had worked a few different part time jobs. I was working part time at a pharmacy with a few other girls when I was given the news that I had HCV and that I would have to have treatment. I rang my employer, the owner of the Pharmacy to inform him. He later came to see me and told me that the other girls no longer wanted to work with me because I had Hepatitis. This really upset me. I still do not know if it was the girls I worked with or simply that he didn't want me there. I was not sure if he was just using the girls as an excuse because either he didn't want me doing that job and/or he couldn't afford to pay sick pay and pay someone else to cover my absences.

21. On one occasion after I had left the pharmacy, I went to GRO-B Dental Practice and one of the girls I had worked with at the pharmacy was working at the reception. Whilst I was registering, she said to me something like "Oh but you have had Hepatitis C". I just couldn't believe it.

22. A couple of weeks ago, I had a tooth taken out and although I had supposedly been clear of the HCV for years (see Section 6 below, re my successful treatment), I still felt obliged to tell the dentist that I had Hepatitis. Similarly, when I broke my wrist recently, I had to tell the nurse that I've had HCV. As soon as I told her she went to the computer and looked up 'haematology', and then informed other members of staff. Although she eventually said everything was fine, it still makes me feel very uncomfortable. I constantly feel like I must tell people who are performing any type of medical procedure on me just so that they are safe. This affects my life greatly.

23. I asked my doctor if I could still be an organ donor as I am 'clear', but I was told that I couldn't, the same would be true of me being allowed to give blood. This makes me question whether I am genuinely clear, or whether I am being deceived. I no longer trust doctors after being infected with HCV and having no one to hold accountable for it. Every year around my birthday I have a HCV test just to make sure that I am still clear.

24. To this day, I am on B12 injections because my body doesn't absorb food. This is because my immune system no longer works very well.

25. What I worry most about is my daughter GRO-B As I said, she was covered in blood when she was born. When she says things like "Oh mum I am so tired", I get so worried. All my family have been tested and nobody has the infection but it doesn't stop me worrying. I constantly think about whether I could have given the infection to my husband GRO-B

26. Another thing that worries me is knowing that when I had a hysterectomy, the surgeons didn't know. Anything could have happened. I have also had other operations such as a hernia and polyps removed.

27. When I used to see my old dentist Mr Shelvey, he would see me before lunch so that they would have time to clean the equipment thoroughly before the next patient. Although this was a rational precaution, it just reminds you that you're not the same as everyone else and this could be very upsetting.

28. In my opinion, my illness hasn't affected my husband very much. He doesn't seem to get upset or go on about it, neither has it changed our sex life. However, I am also aware that this could have happened. After being diagnosed, we were advised to use protection. This should not be necessary for a long married couple and compounded the ignomy.

Section 6. Treatment/Care/Support

29. In 2004 I had treatment for HCV. It was a trail. I took 'Pegasys' (brand) Pegylated Interferon and Ribavirin. I was given leaflets on what the treatment was and the potential side effects. I was then told to have a think about it. I was informed that I have genotype one, which was the apparently the hardest type to cure. The trial was originally due to last for 48 weeks. I consented to have this treatment. I had to inject myself once a week and go for regular check ups at the hospital to find out how I was doing.

30. I also had a liver biopsy and this determined that I didn't have cirrhosis. The biopsy was at Southampton general and it was done with a needle. This was very unpleasant.

31. During my treatment, I couldn't really do very much. I would take the medication on a Friday because it would wipe me out for a few days. By the time I got to 24 weeks I had what appeared to be 'clouds' in my eyes and so I went into hospital. I had also lost about half a stone since the start of the trial.

32. I only ended up doing 24 weeks of the treatment due to the adverse effect that the medication was having on me. However, I was tested and I was informed that the medication had worked and that I was clear of HCV. I believe I was on a trial led by Professor Rosenburg who has since left Southampton and now works in London, I believe.

33. Initially I had six monthly checks but after a while when they all came back clear, I was told that I did not need to keep that up.

34. I have never been offered or received counselling or psychological support.

Section 7. Financial Assistance

35. I applied to the Skipton fund in July 2004. I think I read about it in the newspaper. My doctor filled in the forms and I received the money very soon afterwards. I received £20,000.

36. I now get £4,000 per year, paid in quarterly increments. I also get the £500 heating allowance every December.

Section 8. Other Issues

37. I was given this infected blood in 1972 at a Military Hospital, where I believe I should be able to have confidence in the treatment that I had received. I later understood from my own research, that the NHS, which British Military Hospitals are a part of, had for years been importing blood from America, donated by prisoners and drug addicts

and sex workers. I do not understand how was this ever allowed to happen in the first place but having done that, when was it discovered that people were being given infected blood in the UK? Who knew? What were the screening processes and why didn't they say anything about it?

38. I understand that when you are given blood it is batched and numbered. If they knew which batches were infected, why didn't they contact the people who had been given those batches? They could and should have traced the people who were potentially infected. How many others at GRO-B at the time I was there, were given bad blood? How many people are walking around with an infectious virus, as I was for thirty years, without knowing they have it and therefore risking passing it on?

39. It is so tragic how many people have died. This is why I got involved in the inquiry. I don't want more money; I just think that people or certain departments need to be held accountable for this. It should never have happened in the first place but once it was known, we should have been traced, informed, tested and treated. It is truly scandalous.

40. Within the context of what has happened, I consider myself fortunate that over a period of thirty years from contracting HCV to being diagnosed and then successfully treated, my liver had apparently remained unaffected. That said, I do not know whether it was the cause of other unexplained medical conditions that I have had. I strongly suspect that it was.

41. I still have the very real fear that I could have infected my family or anybody else in the course of living my life. Even though my daughter has been tested and shown to be clear; what if 'they' got that wrong too? My faith in the NHS has been so knocked, that regardless of tests showing the contrary, I worry that my family may have the virus and particularly my daughter, who has gone on to have children of her own.

42. I hope that this Inquiry will be able to give answers to all the infected patients who are still alive and have suffered over many years and continue to do so and also the families of similarly afflicted patients who have not survived. It will not put matters right but it may stop things like this ever happening again.

43. I believe that general assistance, financial and other, is important. The way financial assistance is provided to UK citizens, whether English, Welsh, Scottish or Northern Irish, should be equal as well as British recipients of infected blood and blood products, who are living overseas.

Statement of Truth

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

Signed GRO-B

Dated 19th March 2019