Witness Name: Lynn Johnson
Statement No.: WITN0026001
Exhibits: **None**
Dated: 4th April 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF LYNN JOHNSON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 10th January 2019.

I, Lynn Johnson, will say as follows: -

Section 1. Introduction

1. My name is Lynn Johnson. My date of birth is GRO-C 1950. My address is known to the Inquiry. I am retired with four adult sons from previous relationships. I intend to speak about my infection with Hepatitis C ("HCV"). In particular, I will speak about the nature of my illness, how the illness affected me, the treatment received and the impact it had on me and my family.

Section 2. How Infected

2. I was infected with Hepatitis C on GRO-C 1984 after giving birth to my youngest son at the Hope Hospital, Salford (now known as the Salford Royal Hospital). I had had a normal delivery, but then I started

haemorrhaging after my son's birth. My doctor, Yvonne Holmes, told me that I would need a blood transfusion on this occasion. I had never previously had a blood transfusion.

3. I remember feeling quite ill after having my youngest son. I had already given birth three times before at that point, so I had something to compare the experience to, and I knew that this time was different. I had felt fine after the births of my older sons, but after giving birth to my youngest son, I did not feel quite right. I recall that the hospital gave me a routine blood test sometime after I had the transfusion, but they could not work out what was wrong with me.

4. That pattern remained much the same for almost 20 years until 2003, when my doctors were aware that something was wrong with me but could not identify what it was. I felt very tired after the birth of my youngest child, which did not happen with the other boys so I knew there was something wrong with me. But unfortunately, I had no way of knowing what it was and I did not connect how I was feeling to the blood transfusion I had received after the birth.

5. I underwent relatively frequent blood tests at the hospital, and I did also undergo at least one liver biopsy and a scan between 1984 and 2003. After all this time, it is very difficult to recall exactly what happened when and I may be confusing biopsies that I had before and after my diagnosis. In any case long before 2003, the hospital wanted to check my liver, as they thought that I might have a liver infection. However, nothing was ever mentioned about Hepatitis C or my blood transfusion on those occasions. The doctors only asked me some questions about my lifestyle, such as whether I drank alcohol.

6. I remember that I was awake during my first biopsy. The medical staff told me that they could not do the biopsy with me under anaesthetic, so it was quite traumatic and very painful. The hospital then invited me to go back and have another biopsy under general anaesthetic, which I did. When the results came back, I was very glad to hear that my liver was fine.

7. I did not have many other symptoms between 1984 and 2003 other than tiredness. I did develop depression, something that I did not have before my youngest son was born. I remember going to the doctor and being prescribed some antidepressants. However, I cannot recall any significant symptoms other than that. My tiredness meant that I was falling asleep in my chair by 9pm in the evening after a long day but I did not think that the fatigue was too bad.

8. It was not until 2003, when I was under the care of liver specialist Dr Babs at Hope Hospital, that I was first diagnosed with Hepatitis C. I do not remember all of the details or dates, but I believe I had just undergone further blood tests. I was called into Dr Babs' office, and he told me that I had Hepatitis C.

9. I was very upset and completely shocked when I heard this – Hepatitis C had never been mentioned to me before. I felt like a leper, dirty and different. I was very worried that I might unknowingly pass the disease on to other people, perhaps through a toothbrush or similar.

10. I remember Dr Babs telling me that I could still live a normal life if I looked after myself properly. He told me that the disease could be sexually transmitted. However, no one suggested that my husband at the time should be tested for HCV, nor has anyone suggested it since. My current partner, John, has also never been tested for HCV. I do not believe that either of them have had Hepatitis C.

11. I cannot recall exactly how my infection was linked to my blood transfusion. I think Dr Babs might have asked me whether I had received a blood transfusion in the past. Once I told him of my transfusion in 1984, he was in no doubt that the transfusion was the cause of my infection. I know that this link has been accepted as being the cause of my HCV, as I have received the Skipton Fund Stage 1 payment, though I cannot remember when exactly this discovery was made. I was never given the batch numbers of the units of blood that I received. My recollections are vague

because these events happened such a long time ago. I do not have any copies of my medical records.

Section 3. Other Infections

12. I do not believe that I have received any infection or infections other than HCV, as a result of being given infected blood.

Section 4. Consent

13. I have never had any medical procedures that I did not consent to.

14. With regards to my blood transfusion, I was not asked at the time for my consent, but rather was advised that I needed a transfusion and I agreed. In that situation, if the medical staff had expressly asked for my consent, I would have said yes because I was haemorrhaging and needed the blood. However, of course I would never have consented to receiving infected blood.

Section 5. Impact

15. I was treated for my HCV infection at the Manchester Royal Infirmary ("Manchester Royal"), in the hepatology department. I started this treatment around September/October 2009, I remember this because it was a six-month course and the end coincided with the passing away of my mother in March 2010.

16. Dr Babs initially tried to put me off having treatment, as I did not suffer too much from the symptoms of Hepatitis C. He informed me that the treatment for Hepatitis C was very bad, as the side effects of the treatment were known to be harsh and unpleasant, although he did not explain exactly what the potential side effects were. Dr Babs also informed me that the success rate for the treatment at the time was not especially high. Therefore, he

advised me that I would be better off staying as I was rather than undergo the course of treatment.

17. However, staff at the Manchester Royal advised me that I had the right genotype of Hepatitis C for the treatment to succeed. As a result, I decided to proceed with the treatment.

18. My treatment consisted of injections with interferon, and tablets of ribavirin. I cannot remember how often my injections were. I think they were daily but they may have been weekly injections. I believe I had to take the ribavirin tablets daily.

19. The injections were awful because I had to self-inject. The hospital showed me how to inject myself in the stomach, but I was initially still worried that I would not do it correctly. They did not offer me an alternative to self-injecting the interferon, so I just had to do it.

20. During my treatment, I was attending the Manchester Royal for regular blood tests. On one occasion, the staff said something about my blood count being very low. Thereafter, I had to have two injections each time; one for the interferon, and the other to rectify my low blood count. I do not recall the name of this other drug.

21. The mental and physical effects of the treatment were terrible. I found that I could not do anything – John had to do everything for me. He had to look after me and do all of the cooking and cleaning. I do not fully understand what happened, but I just could not figure out how to do normal, everyday things that I had previously done with no issues, and that really shocked me.

22. I also experienced the rage associated with ribavirin. The Manchester Royal had warned me about this before I started the treatment – they showed me and some other Hepatitis C sufferers a video of a woman experiencing ribavirin-induced rage. I did not take it too seriously at first as I thought that it would not happen to me. But it did.

23. It happened when I was socialising at a pub (I ordered a coke and orange juice), and a man commented on the fact that I was not drinking alcohol. I lost my temper, to the extent that my partner had to pull me out of the pub. Afterwards, I was just surprised that I had experienced the rage that the hospital had warned me about.

24. I lost a lot of weight due to the nausea and sickness caused by the drugs. I believe I lost around one stone in weight. My hair also started falling out. I remember the day when my eldest son first noticed that I was losing my hair. He did not say anything about it because it upset him, but I did not need words to see that he had noticed.

25. I thankfully completed this course of treatment after six months. After the treatment finished, I had to wait a further six weeks to receive confirmed results of the treatment. I remember going back to the Manchester Royal that day. I was very on edge, because I thought that the treatment had not succeeded. Then, the doctor said to me that I was clear of the virus. At that point, I just broke down. I was so relieved that I had responded to my first treatment, as I had found it quite traumatic.

26. I was subsequently discharged from the hospital and now only have to go back for liver function tests every year. Fortunately, my liver so far has been in a relatively good condition and I have not developed cirrhosis or any other medical conditions as a result of being infected with HCV. Nevertheless, I feel that I still suffer from the effects of the infection and treatment.

27. For example, I have suffered from claustrophobia since I was young, but I have found that my claustrophobia has been exacerbated after going through the Hepatitis C treatment. I had panic attacks whenever I was in small enclosed spaces, because I always felt like I was trapped. I also could not stand to be in crowds of people, as I would start to have anxiety. I needed to have cognitive therapy for about 12 weeks at one point, and I

was given medicines to counter my anxiety. I had not needed either therapy or anxiety medication before I underwent the Hepatitis C treatment.

28. I also have fatigue and tiredness, and still suffer from the depression that was first brought about by the treatment drugs. I think it is partly because I cannot understand why this had to happen to me.

29. With regards to my family, my youngest son in particular has also been affected by my infection. He feels very guilty, because I was infected through a transfusion due to a haemorrhage after his birth. He thinks that if it was not for his birth, then I would not have suffered with Hepatitis C. Of course, have told him not to think that way and that it was not at all his fault. Regardless, he still carries unnecessary guilt with him.

30. I divorced my ex-husband just before I received the diagnosis that I was Hepatitis C positive, but I do not think that my condition caused this breakdown in my marriage. I remember having to tell John, my current partner, of my infected status, because it was just at the beginning of our relationship. I felt obligated to tell him because I thought that he might not want to know me anymore, since I had this infection.

31. To this day, there are still some people whom I have never told about my infection with Hepatitis C; it is not news that I want to share with everybody. I told some of my family, and they were initially quite shocked to learn that I had contracted Hepatitis C through a blood transfusion. However, I have mostly kept my infected status private.

32. I always thought that I was the only person in my social circle who had Hepatitis C. I remember going to the GP surgery and seeing numerous leaflets and posters about many different diseases. It struck me that there was nothing there about HCV. There was no information, and it made me feel angry and isolated that people were not being told about Hepatitis C. I thought that I was the only person in the area to have that disease.

33. I recall that I took my treatment for Hepatitis C very privately at home. John had four children from a previous relationship, and I just did not want them to see me self-injecting medication. This meant that I was always quite on edge when I was injecting interferon at home, as I did not want to be discovered.

34. Hepatitis C has also spoiled my social life significantly. I enjoyed drinking alcohol socially before I was diagnosed. It was only after my diagnosis that I retrospectively realised that I should not have drunk as much alcohol, and that scared me. But of course, I had no idea that I had Hepatitis C at the time.

35. Since clearing HCV, the doctor has advised me that I can have the occasional alcoholic drink. Therefore, I do sometimes have a drink, but I am always cautious with my alcohol intake and wary of drinking too much. The thought of damaging my liver is always in the back of my mind, and I am always scared that the virus might come back, so I do not feel like I can just fully enjoy myself if I am drinking alcohol.

36. As a result, I do not drink alcohol most of the time if I am out socialising with friends. I am at a point now where I can go out and enjoy myself, whilst just drinking coke. However, I get a lot of comments from people encouraging me to drink, usually to "get a vodka in that". I have found that in my social circle, there is a stigma attached to *not* drinking alcohol. This was frustrating for me, as I felt like I had to justify why I was not drinking alcohol.

37. With regards to work and financial effects of the infection, I had to give up my job as a result of my illness. This affected my income, as I had planned to carry on working for several more years. I have always done kitchen work, and was working in a school kitchen before I gave up work.

38. I stopped working not long after I was diagnosed, before starting the treatment. I just felt like I could not do my job properly, because I was starting to have more symptoms of HCV, such as bleeding gums and brain fog. The brain fog in particular caused me some trouble at work. The other

women in the kitchen could not understand what was wrong with me, and I could not really explain it. I did tell them that I had Hepatitis C, because I was working in a kitchen after all, and I felt obligated to alert them. But the other women did not really understand the effects of the illness, and wondered why I could not do my job properly as I had been working there long enough to know what to do. This created a very unpleasant atmosphere for me at work.

39. In addition to the brain fog, I was very nervous about infecting other people. I was scared that I would cut myself and accidentally infect the other kitchen staff or the pupils. In the end, it just did not feel right for me to continue in my job, so I handed in my notice.

40. I have never told my dentist about the fact that I have Hepatitis C. I do not recall being asked about this information.

41. Since clearing the infection, I have had some ultrasound scans to check my liver. I requested these checks, because it is always in the back of my mind that the infection might come back.

42. Even though I have received compensation from the Skipton Fund, I would have much rather not had the money than go through the illness and treatment. It was an awful experience, which still affects me now.

Section 6. Treatment/Care/Support

43. I have not faced any difficulties in accessing treatments as a result of being infected with HCV.

44. I have never received any counselling or psychological support as a result of being infected with HCV. It was never offered to me.

Section 7. Financial Assistance

45. As stated above, I receive financial assistance from the Skipton Fund. I received the £20,000 Stage 1 lump sum payment, although I cannot remember when I received this. My eldest son was the one who did the research and found out about the Skipton Fund. The medical staff never mentioned it to me.

46. I also get the monthly payment and cold weather payment. Together, I believe that these amount to just over £300 per month. The monthly payments started just a few months ago.

47. I do not recall much about the application process. I do not think I had any difficulty with it, as Dr Babs asserted there was no doubt that I had contracted the HCV infection from the transfusion in 1984.

Section 8. Other Issues

48. I do not understand why I suffered with symptoms of Hepatitis C without knowing what the cause was for such a long time. I had blood tests and at least one liver biopsy long before 2003, under the care of a liver specialist, yet I was not diagnosed with HCV for almost 20 years. I cannot understand why my HCV was not detected earlier.

Statement of Truth

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

Signed GRO-C

Dated 4/4/19.