Witness Name: GRO-B
Statement No.: WITN0370001
Exhibits:
Dated: 06/11/2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 14 September 2018.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth and address are known to the Inquiry. I am a retired senior research fellow in GRO-B cell biology and worked at GRO-B before transferring to GRO-B in GRO-B in 1984. I have an adult son from my first marriage, and have been married to my second husband for fourteen years (cohabiting for twenty years). I intend to speak about my experience of infection with hepatitis C through blood transfusion.

2. In particular, I will speak about the nature of my illness, how the illness affected me, the treatment received and the impact it has had on me and my family.

Section 2. How Infected

3. I was infected with hepatitis C when I received a blood transfusion following my admission on 19 June 1989 to GRO-B in GRO-B I required a blood transfusion because I was pregnant and suffered a placental abruption. This resulted in the loss of a lot of blood, but I didn't know about it initially because the blood collected behind the placenta. I merely thought that my stomach felt very hard and that I didn't feel very well. I arrived at hospital with dangerously high blood

pressure and, because I had been unaware of the high level of blood loss, I had clotting factors present in my blood. These clotting factors caused me to subsequently develop acute renal necrosis and renal failure. Over the course of the day my condition deteriorated. My baby was stillborn.

4. I was initially admitted into the high dependency unit then ultimately, as my condition worsened, I was transferred into intensive care where I spent five days. During this time I was connected to all sorts of machinery; I was given blood and other fluids very quickly to try and stabilise my condition. I believe that I received six units of blood in total. I have never received any other blood transfusions.

5. No conversation took place between the doctors and myself regarding consent or the risks of infection associated with blood transfusions prior to me being given the blood, but then I wasn't very well.

6. I stayed in intensive care for five days before being transferred to a general ward. I remained in the general ward for another 2 – 2.5 weeks. My recovery took a long time; the doctors said that my kidneys should resume their normal functions within five days, but they didn't. The possibility of needing dialysis was discussed, but fortunately after ten days my kidneys started functioning again and I didn't need dialysis.

7. Six weeks after my discharge from hospital, I went back to GRO-B for a check-up. It should have been a routine check-up, but the appointment has since very much stuck in my memory. The doctor looked straight at me and told me I had abnormally high results in my "LFTs" – liver function tests. Then he started talking about these aberrant blood test results and immediately looked away as he did so. He became strangely rather shifty, and told me that sometimes when you receive a lot of blood, such as six units, the liver is caused to work very hard when these cells die. This is because red blood cells have a finite lifespan of a similar length and after a transfusion the transfused cells therefore die at about the same time. These large numbers of dead blood cells therefore have to be metabolised by the liver at the same time, potentially causing LFTs to rise. The doctor could not look at me while discussing my blood test results and the possible cause of my elevated LFTs. I was struck that he looked away and found it to be very strange.

8. However, I did not think too much about the check-up afterwards and dismissed it as merely a strange experience with the doctor. I was kept busy by my young son (born December 1990) and personal life. I

noticed that I felt tired and did go to see the GP about it, but I was informed that it was normal to be tired given my circumstances – I had a new baby to look after and my first husband had recently left me.

9. Then in 1992, about 18 months to two years after my initial check-up, I watched a *Panorama* programme on television about unscreened blood that was potentially infected with hepatitis C being used in transfusions. It talked about how liver enzymes can go up after a blood transfusion, and how this could be a sign that the transfused patient had been infected with hepatitis C. From watching this programme, it was clear to me that there was a possibility I could have been infected with hepatitis C during my blood transfusion and that the doctor conducting my initial routine check-up had not told me the truth about my abnormal blood test results. So, I then went to the staff health service at GRO-B and requested that my blood was tested for the presence of hepatitis C.

10. I was at work a couple of days later when the staff health service called me and asked me to make an appointment to go and see them as soon as possible. As they were already on the phone to me, I asked the lady on the other end whether my test had come back positive. She initially did not want to tell me over the phone, but I pressed her and she confirmed that the test was indeed positive for hepatitis C.

11. Initially upon hearing this news, and not knowing too much about hepatitis C, I did not think anything about it other than "Oh dear". I immediately then read some literature and did some research about hepatitis C, and found that 25% of people with hepatitis C die within 20 years. I felt quite emotional upon reading this and because I found it so upsetting, it was difficult for me to read and analyse further. I therefore decided to speak to my partner (who became my second husband) about it.

12. My husband was a pathologist and Professor of GRO-B at GRO-B He also ran a very successful research group there, so he was used to looking over data. He then spent a long time carefully reading through the literature and thoroughly going over the data on hepatitis C for me. He was able to reassure me that the figures were not as bad as I had first thought. My husband explained to me that the statistics I had read were obtained from people who had already presented with liver disease, so the figures were actually 25% of hepatitis C-infected people with symptoms of liver disease died within 20 years, and not 25% of the total infected population. The disease was still poorly documented in these early days and the figures in the

literature were derived entirely from people who had already presented as being unwell. I, on the other hand, would probably never have known that I had hepatitis C had I not taken myself to be tested. My ultrasounds and subsequent LFTs have always been normal, so there would have been no reason for anyone to suspect I had hepatitis C. My husband really tried to reassure me on this front.

13. Regarding information that was given to me by the hospital about hepatitis C, I went back to see staff health following my phone call and was offered an appointment to see an infectious diseases consultant. One of the nurses there told me not to share toothbrushes and to be careful with blood contamination. It is hard to remember what other risks I was told of and what I read about myself. I was aware that there was a slight risk of transmission of hepatitis C through sex and through blood, but I cannot be sure whether I was told about it by the medical staff or whether I read about it myself. I was just told of some risks in one of the offices they had, but it was a casual meeting at the time as they were already going to arrange for me to see the infectious diseases consultant fairly quickly.

14. The consultant who I saw was very nice. He did some more liver function tests and checked that everything was functioning as normal. He assured me that the size of my liver was fine, and again talked me through things like not sharing toothbrushes. He also mentioned the risk of vertical transmission, but reassured me that it would be quite rare to have vertically transmitted hepatitis C to my son. At no stage was it suggested that my son or husband should be checked to see if they were carrying the virus.

15. I suspect that we further discussed the risks of hepatitis C and transmission but not in any great detail, though I don't remember precisely. It would have been presumed that I was intelligent enough to know what to do and where to look for further information; we were familiar with each other as we worked within the same research division at GRO-B albeit in different departments, and we used to come across each other quite frequently. The consultant was aware that I worked in a laboratory, and was used to working with blood and needles.

Section 3. Other Infections

16. I do not believe that I have been infected with any other diseases as a result of being given blood or blood products. We were immunised

against hepatitis B at GRO-B as soon as we started working there and then had boosters for as long as they were required.

Section 4. Consent

17. I believe that we were routinely tested for HIV at GRO-B when I was pregnant with my son. I recall that we were asked to consent for HIV testing, but I don't remember whether I signed something.

18. I did not expressly consent to the blood transfusion, but at the point that I needed it I was quite unwell and needed the blood to stabilise my condition.

19. I do not believe that I have otherwise been treated or tested without my knowledge, consent, without being given adequate or full information, or for the purposes of research.

Section 5. Impact

Mental and Physical Effects of being Infected

20. As I have mentioned above, I did not suffer any other physical effects of hepatitis C other than feeling tired. Moreover, the only time I felt tired was when I had my young son, and so it was not clear whether the source of my tiredness was from hepatitis C, or from having a toddler and working full time at the same time.

21. Yet the disease did have a greater effect on me mentally. I felt that hepatitis C was always a threat, especially as I had a child and 25% of people with symptomatic hepatitis C developed liver cancer within 20 years. This always used to prey on my mind when I was due to have a blood test, liver ultrasound or fibroscan. I would take myself for a blood test every six months at the hospital, and although my blood tests usually came back normal, I was always worried that the next blood test would be the one with dreaded results. It was terrible for me in the period from about two to three weeks before I had a blood test up until I received the results. I was the same before my liver ultrasound scans and fibroscans.

Further Medical Complications or Conditions Resulting from the Infection

22. Thankfully, my blood tests all came back normal as did my liver ultrasounds and fibroscans and I have not suffered any further medical complications as a result of hepatitis C.

Impact of Treatments

23. However, I suffered some truly awful side effects when I eventually started treatment for my infection in September 2007. I was originally supposed to be on a course of pegylated interferon alpha with ribavirin for 48 weeks, but the side effects of these drugs were so terrible that I had to be taken off them early.

24. My red and white blood cell counts dropped, my hair fell out, I had a lot of itching that made it difficult to sleep, I lost a stone and a half and eventually it got to the stage where I could barely leave the house as I was so exhausted. After approximately 38 weeks of treatment, I started to get heart arrhythmias following the weekly injections of interferon. After each subsequent weekly injection I suffered more and more heart arrhythmias so that by about 40-41 weeks of treatment, every other heartbeat was ectopic and I could barely stand up. I went to the hospital and the doctors took my condition very seriously. They immediately gave me an electrocardiogram. My blood pressure was also dangerously low, dropping down as low as 60/40. These results caused them to consider admitting me to the cardiac intensive care ward in the hospital. However, it was then decided it would be safer for me to stay at home as my low white blood cell count placed me at risk of getting a serious infection.

25. At the time when my admission into hospital was being considered, my consultant was out of the office so he had to be relayed all the information over the phone. My stepson happened to be a cardiologist at GRO-B and my husband drove me there to have an echocardiogram as I couldn't have one at GRO-B the same day. He found that there was nothing structurally wrong with my heart, but rather my ectopic heartbeats were caused by problems with the electrical activity of my heart.

26. I recall that following this diagnosis, my consultant called me when we were on our way home from hospital in the car. It was a telephone call that I will not forget. He said to me, "GRO-B please stop the treatment; promise me you will stop the treatment. We don't want to lose you." He knew that my heart arrhythmias and very low blood pressure were very

unusual side effects of the treatment that were only very rarely seen. When we further looked into these issues afterwards, we found that there was only one other reported case where a patient had suffered the same side effects. He had died despite the fact that he was being monitored in hospital.

27. I then immediately stopped the treatment and spent the next three weeks in bed with ectopic heartbeats. I just slept for most of this time. My husband stayed with me and every time I woke up he was taking my pulse. My consultant talked about the possibility of having to have cardiac ablation treatment to correct my abnormal heart rhythm and I was referred to a cardiac consultant at GRO-B Luckily, this was unnecessary in the end and it was a just a matter of resting and getting the drugs out of my system, which took about six months.

28. I started my second treatment in September 2016. By that time, my original consultant had retired and I had been transferred to the hepatology department at GRO-B I took a twelve-week course of treatment with new drugs, namely Viekirax, Exviera and ribavirin, which I finished in December 2016. Unfortunately, like the first treatment when I took ribavirin, my red blood cell count dropped very quickly so that I became anaemic. My dose of ribavirin therefore had to be reduced, but thankfully I was able to stay on high dose ribavirin just long enough for the treatment to work before it had to be reduced to minimise the adverse side effects.

29. The other two drugs made me feel like I had the flu – I had flu-like symptoms and felt very tired. I had to slow down a lot and stop doing things because I couldn't. For example, my husband and I had a couple of incidents where we tried to go to the theatre but then had to leave halfway through the performance because I felt extremely unwell and almost fainted. I just needed to rest. After the second incident, we decided not to go out again until after I had finished the course of treatment.

30. Fortunately, the second treatment worked brilliantly for me. I would have preferred to have been given one of the other new treatments available that did not include ribavirin, having reacted badly to it in the past. Nevertheless, I was quite happy to proceed with the course of treatment and it was only 12 weeks so it was much easier to tolerate than my first planned 48-week course of treatment.

31. I am now clear of hepatitis C. After I completed my second course of treatment, I went back to hospital a few times to check that my

haemoglobin levels had recovered and that the treatment had been effective. Fortunately, a year after I finished my treatment, I received final confirmation that I was clear of hepatitis C and I can happily say that I no longer have the virus.

Impact on Treatment, Medical and Dental Care for Other Conditions

32. I was still able to access medical and dental care whilst I was infected. However, I always felt awful whenever I had to go the dentist. I always had to have the last appointment of the day because all of the equipment had to be thoroughly cleaned after me. That was my dental surgery's health and safety rule. I understand the reasoning and rationale behind it, but it still just made me feel bad and that my blood was dirty.

Impact of Stigma

33. Because of the stigma associated with hepatitis C, it was very difficult for me to tell people about my infection. Some of my close friends were aware of my infection, but some friends I only told when I started the treatments and had to explain why I suddenly looked like a chemotherapy patient. I didn't like to tell many people in general because of the stigma attached; I felt like there was always an assumption that I had used intravenous drugs or contracted hepatitis C in another way that was not as innocuous or blame-free as a blood transfusion.

34. These questions always came up whenever I was applying for travel insurance or life insurance; I was always asked whether I had used intravenous drugs or had tattoos. Having to go through these questions every time and tell people of my infection made the process of getting insurance that much harder.

Impact on Private, Family and Social Life

35. Obviously my infection with hepatitis C impacted on my family life. The threat of developing further symptoms and complications related to hepatitis C was always there in the background. My close relatives all knew of my infection. They were aware that sometimes it was difficult and sometimes it wasn't. They knew that I would get very pent up and anxious a few weeks before I was due to have another blood test, liver ultrasound or fibroscan.

36. As my son was so young at the time when I was first diagnosed with hepatitis C I didn't tell him about my infection until much later. I finally told him in 2007, when I was just about to start my first course of treatment. He was about 16 years old at that time. When I was undertaking my first course of treatment, my son was doing his 2 year International Baccalaureate course at school and hoped to get a place at Oxford University to read English.

37. When I initially told me son about my infection back in 2007, he looked like a rabbit caught in headlights on hearing the news that I had hepatitis C. This inevitably had some impact on his academic performance, particularly during the later stages of the treatment when I was clearly very unwell. My son did not want me to inform the school of my medical condition initially, but I told the school eventually because I thought that we should ask for mitigating circumstances to be considered in my son's final exam results. These results clearly showed that he had underperformed in some of his coursework submitted during the latter part of my treatment. The school were very supportive to us during this time and reassured us that we did not have to worry about my son's admission to Oxford, and thankfully they were correct.

38. With regards to my husband, he was extremely supportive during both my periods of treatment. He was always very pragmatic and when I was first diagnosed with hepatitis C, he spent a long time trying to gather evidence to reassure me that mortality rates were not as bad as I had initially thought. He really reassured me over the data and spent a lot of time looking after me when I was undergoing treatments.

Impact on Work and Finances

39. As I did not suffer many physical symptoms of hepatitis C, the infection had relatively little effect on my work unless I was undergoing a course of treatment. I had retired by the time I started my second course of treatment, but I had to leave work for a period during my first course of treatment, although I still tried to go in when I could and just leave when I had to. My job was such that it was very flexible and it was up to me what I did, and my husband was my boss so he was of course very understanding and supportive of me. At the beginning of my treatment, I would still go in and do some work in the morning, then go home and sleep. However, I had to stop completely when I started getting arrhythmias and then had to slowly build up strength to go back to work full time again once I'd come off the treatment. My colleagues were supportive and got used to me not being able to stand for very long and being tired.

40. Financially speaking, the illness did not have much impact.

Section 6. Treatment/Care/Support

41. I did not experience many difficulties in obtaining treatment for hepatitis C. I was never offered counselling services but I did not seek it either.

42. I believe that GRO-B looked after me very well. I had a very flexible arrangement with my first consultant from very early on after my diagnosis. I would always take myself for my blood tests every six months and my consultant had an open door policy whereby I was always welcome to go and see him. I had a formal appointment with him annually. I was given diagnostic examinations with access to the new technologies available at the time. For example, I had fibroscans every 18 months to 2 years as soon as this replaced older ultrasound techniques for examining the liver. A fibroscan measures the degree of elasticity in the liver, which is potentially a much better marker for measuring the progression of liver disease than LFT results.

43. Although I did not undergo my first course of treatment until 2007 – a long time after I was diagnosed with hepatitis C – this was by my choice and I was offered the treatment from the very start. However, my consultant advised that I wait for newer and better treatments that he knew were in development, particularly as the available treatments were not especially effective for the genotype of hepatitis C that I had. My liver function tests, ultrasounds and fibroscans always showed normal results. The originally available treatment only had a 40% chance of success for me. Therefore, I was advised to wait for the newer treatments to be made available, unless something went very wrong in my test results. I would see the consultant to discuss treatments at yearly intervals, and would always decide to wait for the new treatments as there was no clinical suggestion that I needed to take action against the infection; my blood tests were always normal.

44. However in 2007, the new treatments were not being developed and made available as quickly as my consultant had originally anticipated, and there was evidence to suggest that interferon and ribavirin treatment could be more effective if the patient was under the age of 50. I would have been 50 in 2010, so I decided to have the treatment. Unfortunately it was not effective for me and I had to come off the treatment early because of the potentially life-threatening side-effects.

45. Then I started my second course of treatment in September 2016, a 12-week course with new drugs. As the treatment was very new and expensive, there was a gradual roll-out period, where those with more severe symptoms of hepatitis C were treated first. Of course that was right and I understand the reasoning behind it, but it meant that I had to wait for about a year before the treatment was made available to me. This was frustrating at the time. I tried to participate in a clinical trial so that I could try one of the new treatments earlier, but I would have been abroad for two weeks of the trial and, although I had been offered a place, ultimately I was not allowed to join the trial because of this. I wish that I had been offered one of the treatments without ribavirin, but I am otherwise happy with the care and treatment I received.

Section 7. Financial Assistance

46. I have received financial assistance from the Skipton Fund since 25 March 2011, when I received my first payment. Prior to my application a few weeks before that, I had not heard of the Skipton Fund. I do not recall how I found out about it, I believe I must have read or heard about it on the news somewhere. I then mentioned it to my consultant, and he was very surprised that I hadn't applied for it before. He had presumed that I already knew about it and had submitted my claim.

47. I then completed my application forms and my consultant completed his part of it. After I submitted my form, the Skipton Fund emailed me to tell me they had received it and would let me know regarding the outcome of my application. Quite quickly afterwards they informed me that everything was fine with my application, and then transferred me a lump sum of £20,000 on 25 March 2011. This was the initial stage 1 payment.

48. I now receive the regular stage 1 payments for hepatitis C, firstly from Skipton and now from the NHS Business Services Authority (BSA), when they took over from the Skipton Fund. I received the new payments from the BSA as soon as it became available; for me the process of transferring to the BSA was very smooth. I believe the BSA was announced in July 2016, and the first year of one-off payments were paid and backdated from 01 April 2016 to March 2017. I received £3,500 which included a winter fuel payment of £500. Now I get monthly payments, and the allowance has gone up since April 2018 so I received around £333 per month.

Section 8. Other Issues

49. I recall being informed by the hospital that samples of each unit of donated blood were always kept so that they could be checked, but I do not know anything further about this or whether anything was done.

Statement of Truth

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

Signed GRO-B

Dated 12/11/18