Witness Name: GRO-B
Statement No.: WITN1900001
Exhibits: WITN1900002-WITN1900006
Dated: 12 December 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1. Introduction

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

2. My date of birth is GRO-B My address is known to the Inquiry.

3. I live in GRO-B with my husband. We have three children who have all now grown up and moved away from home. I trained as a GRO-B GRO-B qualifying in 1982, and have worked as a GRO-B GRO-B I retired at the age of 38 due to ill health. I have tried to continue with voluntary work but suffer with fatigue.

Section 2. How Infected

4. I was admitted to GRO-B Hospital, Bristol, GRO-B GRO-B on GRO-B 1985 for the delivery of my second child, and

discharged on GRO-B 1985. I had my son at 7.30am and the notes state the placenta was 'apparently complete' (**WITN1900002**), however I was not well and collapsed twice over the course of the next few days. Two days later I had a scan and was diagnosed with retained products. I was taken to theatre for D&C (dilation and curettage) and they removed 568mls of retained products. I lost a lot of blood during the procedure and a blood transfusion was suggested. At 1.05pm on GRO-B 1985 I was given the first of two bags and it was this first bag which infected me. The batch number was 142860 (**WITN1900003**). I was given the second bag shortly afterwards.

5. I was discharged home and felt very unwell. I was exhausted for a long time after the birth and thought it was post natal depression. The exhaustion continued and I always felt as though I was coming down with something: I never felt quite right again. I suffered with episodes of flu like symptoms and achy joints for years. I thought perhaps I was a little depressed and questioned my mental health, which was very frightening. Things would clear for a month or so and I would feel ok, before the symptoms came back again, like a fog descending over me. I was scared to tell anyone in case they thought I had post natal depression. From my work as a GRO-B I knew how post natal depression was dealt with and I was worried about the implications as I didn't want my children taken away from me. I carried on with things and just had to accept that that was the way things were.

6. Although I tried to return to work as a GRO-B with GRO-B GRO-B the amount of time I needed to take sick because of my health became embarrassing. Although the job was stressful that did not seem to account for why I felt so unwell. I took early retirement in 1997 due to the HCV.

7. I went to the doctors from time to time and would explain how I was feeling, but there was always an excuse. My husband worked shifts and I was on call which was disruptive, or having the boys was naturally very tiring. The General Practitioner would suggest that perhaps I was not eating or sleeping properly,

and would advise me to change my lifestyle. I was not asked for blood tests or liver function tests.

8. When I received the infected blood no information or advice was provided to me about the risk of being exposed to an infection. I had a complicated delivery. I was told that a blood transfusion would mean I would recover more quickly and be better able to cope with my young family at home. No one said anything about any risk of infection through blood and I felt that I had no choice about having the transfusion.

9. As a result of being given infected blood I was infected with Hepatitis C (HCV).

10. I found out that I had been infected with HCV as follows.

11. In May 1996 I had a letter out of the blue from my GP, who I had been with since 1983 when I moved to the area, telling me he had been contacted by the Look Back scheme and asking me to make an appointment and have a test. The letter said not to worry as I didn't have HIV. I booked an appointment and went to see him. He explained the Look Back scheme was doing tests because some people had been exposed to HCV. I had not heard of the virus and the GP said he had not heard of it either. I was the only person at the surgery identified through the Look Back scheme. The GP took my blood and two days later he called me to ask me to come back to the surgery. My GP told me I had been exposed to HCV. He also referred me to a hepatologist at the Bristol Royal Infirmary (BRI), which was the same Trust which infected me.

12. In July 1996 I had my first appointment at the BRI with the hepatologist who told me I had been exposed to the HCV virus from the blood transfusion I had received back in 1985, 11 years earlier. He examined me and told me I was a healthy young woman who did not inject drugs or drink much alcohol, so he said he didn't think I would have a long term problem. The hepatologist was vague, however he sent me for a liver scan. He said I would be monitored and

they would see me again in clinic in a few months' time. He advised testing my husband and my three children. I had contracted the infection after the birth of my second child, whom I had breastfed, and I then went on to have a third child in 1990 so this meant that my third child was at risk of having contracted the infection from me.

13. I had to go through the trauma of explaining to my husband that he may also be infected. My youngest child was six years' old and I had to watch him go through his first ever blood test because of something I could have transmitted to him. That was the single most difficult experience of the whole diagnosis. The whole family was tested at the same time and, thankfully, all their results came back negative.

14. The GP provided me with no information about the infection at the time he diagnosed me. When I then went to see the hepatologist after the GP referral the only information I was given was that I should get the whole family tested. The basic information I received was that I had the infection and they didn't know how it would progress but that they thought I was ok because I was young and healthy. I asked the consultant if I was going to die, because I had three children, and he said, 'I hope not'. When I asked questions about my long term prognosis they said they didn't know. They had no leaflets and no advice. A colleague of his told me to "go and have a nice summer". My main source of information was the British Liver Trust, which I found by my own research. They sent me information about HCV The Haemophiliac Society were also helpful.

15. I feel I was not provided with adequate information to help me understand and manage the infection. I believe that the information should have been provided to me earlier, from the moment I was first diagnosed.

16. My GP was kind, but knew nothing about the infection. The consultant at the BRI was not unkind, but there was an air of indifference. I was a young woman

in my thirties with a young family and a job. I was completely devastated. I felt the hospital were rather dismissive of me.

17. Although I was advised to have my family tested, I was not given any other information about the risks of others being infected as a result of the infection. I had to learn things myself about not sharing toothbrushes, scissors, nail files, etc.

Section 3. Other Infections

18. I do not believe that I have received any infection or infections other than HCV as a result of being given infected blood. There was, however, a misdiagnosis of HIV some time later, which was very distressing. When I started treatment in 1999 it was arranged with the hospital that I would have my blood tests done at the GP surgery to save the extra travel to the hospital. The GP called me in to say that one of the forms he had received from the hospital said I had HIV. He called me and said, 'have they told you, you have HIV?'. I was very concerned and the GP told me to have my children tested for HIV. I had to go home and tell my husband that we all may have to go through the testing process again, this time for HIV. The hospital then told us it was an error and that they had recorded the infection as HIV rather than HCV. I had just commenced treatment and was very unwell and unable to deal with this news. So my GP followed it up and dealt with the complaint letter on my behalf. He made sure there was a note on the file to explain it was an error on the hospital's part, but it took weeks to resolve and was a frightening and very alarming time.

Section 4. Consent

19. I do not know whether I have been treated or tested without my knowledge or consent, or for the purposes of research. I know that I was the first person to

receive the new combination treatment for HCV at the BRI (see below), so I suspect they were monitoring me in that respect.

Section 5. Impact

20. The mental and physical effects of being infected with HCV but not being diagnosed included me doubting my sanity, as I have set out above. This was the most difficult part of being diagnosed.

21. The mental effects of finding out about the infection were as follows. At first, a very small part of me was relieved when I was diagnosed because there was finally an explanation for how I had been feeling which meant there was nothing wrong with my mental state. I was also relieved at the thought I could now lead a normal life without fearing for my mental health, but this concern was quickly replaced with new fears, including becoming acutely aware of my own mortality and the knowledge that I might die earlier than expected and leave my children motherless. It felt like going through a grieving process that finally leads to acceptance.

22. Although I have undergone treatment and the virus has been ‘cleared’, I will never be ‘cured’ even though the virus has been inactive for many years. They can never tell you that the virus will not come back and affect you. This infection becomes part of you and part of your life. I think I have now accepted it, but for many years I was unable to.

23. In my darkest moments I question whether I will die from my liver or from my aneurism (see below). I hope it is my head, as it will be quicker, I would rather not die from my liver. I often think about the fact that I carried my third child and gave birth to him in 1990, when I was already infected with the virus. The medical records say that I had a bleed at 28 weeks pregnant with him and I can see from the records that they tested my blood and said, ‘blood test recommended due to BT in 1985’, yet no one told me this

24. In terms of medical complications or conditions which have resulted from the infection, I have tingling sensations, joint pain, arthritis in my hands and ankles, and I suffered strokes in 2000 and 2014. As a result of the stroke my eyesight is not very good. I have medical report stating the areas of my brain that were affected and what brain damage I have been left with since the first stroke in 2000. As a result of the strokes I find reading text in a book and writing anything down very difficult. I find I am not so quick at thinking and have learnt to lip read because sometimes my hearing fails. I have had various tests and know that I am unable to follow more than three steps in a list of instructions. I am also left with nerve damage in my leg and can sometimes drag my leg when walking.

25. The treatment I have been given for HCV is as follows. My consultant told me that he suspected I had genotype 3 but he said he didn't want to find out in case I was one of the ones they couldn't treat well. My PCR test in 1998 showed the HCV was chronic and active, which I was told meant that it was getting worse and my consultant said would eventually cause me cirrhosis. I also had a liver biopsy on 20 February 1997 which showed the virus was active.

26. In 1999, three years after diagnosis, I became aware of the then new treatment which started in 1999. Initially my request for treatment was refused as my condition wasn't considered severe enough. With the help of my husband and local MP and after numerous letters of complaint I was eventually offered the new treatment of Interferon and Ribavirin on a 24 week programme. I was shown how to inject myself and take the Ribavirin. The treatment made me very weak, I lost a lot of weight, my hair fell out, I suffered with nausea and felt quite depressed.

27. Two weeks before I was due to finish treatment on 28 February 2000 I suffered an aneurism causing a sub-arachnoid haemorrhage and was taken to Frenchay Hospital. On 2 March 2000 I had an operation to coil the aneurism, returning for an angiogram on 25 September 2000 to check my blood vessels

when it was discovered I had had a further aneurism as the first procedure had caused damage to my blood vessels. Further coils were inserted. Three days later, in September 2000, I suffered a stroke. There was also damage to my femoral artery and as a result I have a weak leg which required extensive repair. **WITN1900004** is a letter dated 23 March 2001 from Dr GRO-B GRO-B Consultant Neuropsychologist at Frenchay Hospital, setting out the history of the subarachnoid haemorrhage, my cognitive symptoms, cognitive tests and her recommendations. The letter clearly describes the difficulties I have experienced since the haemorrhage.

28. I know that the treatment for HCV makes you anaemic and weakens the blood vessels but when I asked whether the haemorrhage was caused by treatment for HCV the doctors said they didn't know. They mentioned there could be a family history of haemorrhage and stroke, but there is no such history in my family. Two of my children have subsequently had scans and they do not have weak arteries. I was asked whether I wanted to continue with treatment for HCV but I decided against it as I believe it was the treatment that caused the brain haemorrhage.

29. **WITN1900005** is the EIBSS application form completed by Dr GRO-B on my behalf. At page 12 of the form Dr GRO-B states as follows, in the clinical assessment:

> GRO-B experienced a non fatal subarachnoid haemorrhage in Feb 2000 after a right anterior choroidal artery ruptured. This was coiled but further bleeding occurred in Sept 2000 requiring further neurosurgery. The SAH occurred during treatment with Ribavirin + Interferon + there is thus a close temporal relationship with antiviral treatment. The risk of haemorrhagic stroke is increased in those with Hepatitis C and there are case reports suggesting an increased risk of aneurysmal bleedings well. The following could have contributed to an increase risk of spontaneous bleeding from an aneurysm namely: Hepatitis C associated vasculitis; hypertension w/ treatment + anxiety

w/ treatment; treatment related blood dyscrasias; stress of Hepatitis C infection + [illegible] treatment. The resulting psychosis, cognitive + physical disability has left GRO-B unable to work in her previous GRO-B role and reliant on her partner + family for some care needs.' I believe this assessment clearly links the sub arachnoid haemorrhage to my HCV.

30. I faced great difficulties in accessing HCV treatment I received and it took months before treatment was granted. I heard that new treatment was available in May 1999, and went to see the consultant who told me I could not have treatment because I was not bad enough. I wrote many letters to the Chief Executive, UBHT, GRO-B asking for treatment, explaining how I had become infected, my prognosis and highlighting the unfairness of having to wait until you are at death's door before being given treatment. I also involved my GP who wrote many letters for me. Some of the responses I received from the Trust were very distressing and blamed the HCV on my lifestyle and it was my hepatologist who had to step in and explain that in fact it was the Trust who had infected me. The first haemophiliac to die of HCV died at the BRI in 1984, so they were aware of the situation. **WITN1900006** are some of the letters I wrote fighting to be treated, and the responses I received.

31. I found the whole experience of fighting for treatment nightmarish and could not believe they had accused me of bringing the virus on myself. Eventually the hospital agreed to treat me and I was the first person to receive the combined treatment . At that time I attended the liver clinic at the hospital but once treatment was agreed they moved me to another clinic because they thought other patients would be angry that I was receiving treatment when others were not. I asked how many patients there were who had been infected like me and my consultant told me there were around 65 patients, but that he had to select who he could treat because he couldn't treat everyone.

32. I do not believe there are any treatments which I ought to have been offered but was not.

33. As a result of the way I contracted the infection and my subsequent treatment I have lost trust in the medical profession.

34. The impact of the virus on my private life nearly caused my marriage to break up on two occasions over the years. Although our relationship has survived it has been very difficult, mostly because of the guilt I feel. I blame myself for putting us in this positon, especially financially. We didn't expect to think about money constantly.

35. My husband worries about me a lot. He is my carer and has needed to arrange his shifts around my care and hospital visits, as well as working full time, and the extra burden has certainly taken its toll on him visibly as he has aged very quickly with the worry and stress. My husband has his own health issues but has not been able to retire as his is our only income. We have had to fight for everything, including for me to have access to the treatment (see above), and these battles have affected us all.

36. The virus has changed our lives completely. I can no longer work and we do not have a good retirement to look forward to as a result. I cannot fly so we cannot take flights to go on holiday (and I used to love to travel), and I cannot drive so am more dependent on my family.

37. The infection has impacted on my husband's job because he has to care for me. Even more since the brain haemorrhage. He had to tell his employer about my HCV status. He can no longer work nights because sometimes I need help getting to the bathroom during the night. He has been put on desk work as a result and has never progressed in his work as he would have hoped to, and has never been able to go for promotion. When he wanted to apply to work elsewhere in the country he could not do so as moving house might have affected my entitlement to treatment as it can be a postcode lottery as to which hospitals will offer it.

38. In terms of our family, the children have grown up with me being ill. I shielded them from the virus by not telling them about it and they were too young to

remember having their own blood tests for HCV. They were aware that I was on treatment because I was injecting at home. I have only recently told them about how I contracted the virus because of the media attention of the Public Inquiry.

39. Over the years I feel that they have missed out because of my infection and treatment. I have missed attending their football tours, and could never go camping with them because of my arthritis. We could never afford to go on the sorts of holidays that their friends went on because of our reduced family income.

40. The virus has affected my social life because I was always worn out. There was always an element of fear with any social engagement as to whether I would get through it. I used to get very muddled with speech and would say words out of sequence in a conversation which greatly affected my social interaction causing me great embarrassment.

41. I have now lived longer with this disease than without it, yet I live in a close of 12 houses and no one here knows. The virus is very isolating: you don't want to tell anyone about it because you don't want to be ostracised, but even if I had told people so little was known about the virus at the time that they wouldn't have been able to understand what I was going through. I told one friend who now lives abroad. I have close friends I have never told. Even my extended family do not know. I once made the mistake of telling a friend of mine who had offered me some administrative work after I was forced to retire from GRO-B She said she would mention it to the other staff in the office and suddenly no one wanted me to make the tea when it was my turn or wash up their cups. I felt very uncomfortable as I realised that they did mind, so I left. I would rather no one knew about the virus.

42. The stigma associated with a diagnosis of HCV affects many aspects of our lives, from medical to dental treatment, to my husband's job, to the stigma I experienced when people at work found out. In a strange way, the brain

haemorrhage helped with the stigma because then I had a more socially acceptable illness than HCV. The brain haemorrhage is something I can tell people about and they accept that as an explanation for what is wrong with me.

43. In terms of the impact on work, as I have described above, I had to give up working in my role as a GRO-B with GRO-B due to ill health. Working for GRO-B meant that I wasn't treated too badly but I could tell they didn't really want me once they knew about the virus and were quite happy for me to be pensioned off. I took on the administrative role working with a friend for a few hours each week before I suffered the brain haemorrhage but since the haemorrhage I have been unable to work.

44. Financially, the infection has affected us greatly. I have been completely unable to work since the brain haemorrhage. I was unable to work during treatment and my pension is much less than I would have hoped as a result. My husband is unable to get a promotion so our family income has been greatly reduced.

Section 6. Treatment/Care/Support

45. I have never been offered counselling or psychological support in consequence of being infected. I think I would find it difficult to discuss with anyone, but it would have been helpful if such a service had at least been offered.

46. I have seen copies of my medical records and can see an entry when I was referred to hepatology at the BRI describing me as an anxious woman and recommending counselling, but this was never discussed with me and counselling was never offered.

Section 7. Financial Assistance

47. No one ever contacted me to offer financial assistance from any of the Trusts or Funds set up. I found out about the Skipton Fund through the information sent to me by the British Liver Trust. In March 2004 I received the Stage 1 payment of £20,000 from the Skipton Fund. I had to supply evidence to them from the BRI and it took months to receive the payment. The process added another level of anxiety to our lives, nothing about this condition is ever easy. Two years after I applied to the Skipton Fund they wrote to me and asked whether I was aware of the Caxton Fund. I had not been aware of it and could have had free prescriptions and the winter fuel payment during those two years, but I could not claim retrospectively. Even applying for the winter fuel payment involved many forms.

48. When EIBSS took over from the Skipton Fund and the Caxton Fund they sent me more forms to complete. I now receive the SCM payment of £1,500 per month, which has completely changed my life and I have been able to think about paying for dental treatment. In order to receive this payment I had to see my hepatologist to prepare a report. We paid privately to see the hepatologist in order to speed up the process and get the forms completed. I also receive PIP and ESA in relation to my brain haemorrhage and consequent loss of mobility.

49. The process has been very difficult and I always felt like we had to beg if we wanted anything from the Caxton Fund. We asked for financial support when my mother-in-law was dying, as my husband also cares for his disabled brother, but the Caxton Fund declined our request and referred us to social services.

50. The SCM payment has taken a lot of financial pressure away and we hope my husband can now retire. However, I struggle to see how a value can be placed on someone's life. I used to earn a good salary and my ability to earn has

been taken away. I would much rather not have had this virus, and have lived a normal life.

Section 8. Other Issues

51. I hope the Inquiry process will achieve acknowledgement that mistakes were made and identify who is responsible for those mistakes.

Statement of Truth

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

Signed GRO-B

Dated …12 December 2019……..