Witness Name: GRO-B
Statement No.: WITN1026001
Exhibits: WITN1026002 – WITN1026016
Dated: 14th October 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1: Introduction

1. My name is GRO-B My date of birth is GRO-B 1950. I reside at GRO-B I am now retired. I married my husband in 1970 and we have a daughter and a son, both of whom are now adults.

Section 2: How Affected

My experience of treatment with blood products

2. I have Von Willebrand's disease and as a result I have, on occasion, received blood transfusions and blood products. In 1961 I had two teeth removed at St Thomas' Hospital which is part of Guy's and St Thomas' NHS Foundation Trust. This was the first time I was told by Dr Ingram that I had Von Willebrand's disease, as prior to that the bleeding disorder did not have a name. I was registered on the haemophilia database and given a card to carry around. At that time, the treatment for a bleed in my mouth was biting on gauze until the bleeding stopped.

3. The first time I received treatment for Von Willebrand's disease was in 1968. I was 18 years old and I had my wisdom teeth removed. I was in St Thomas' Hospital for one month and the treatment I received was Cryoprecipitate.

4. In 1979 I gave birth to my son. As a result of having Von Willebrand's disease, I could not have a caesarean section, although he was a large baby at 8lb 12oz, and so I had a natural birth. I was in labour for 33 and a half hours and the birth damaged my bowel and perineum, meaning I required numerous blood transfusions, Factor VIII and Cryoprecipitate. I was in hospital for three months and I nearly died. Thankfully, although it took nearly a year, I did recover from this.

5. In approximately 1980 my husband and I began trying to conceive another baby. After 16 months of being unable to conceive, the doctors thought my fallopian tubes may have been blocked following my first pregnancy and so I had agreed to have my fallopian tubes blown open.

6. I then found out that I was pregnant in 1982, but unfortunately I contracted German measles when I was five and a half weeks pregnant. As a result of this diagnosis and the likely impact on the baby, we elected to have a termination at St Peter's Hospital, which is part of Ashford and St Peter's Hospitals NHS Foundation Trust. I was given fresh frozen plasma prior to and Factor VIII during the suction termination of pregnancy on 30 June 1982 and I was discharged on 5 July 1982.

7. However, I was readmitted on 19 July 1982 following severe bleeding. Again, I was given Factor VIII, fresh frozen plasma and a blood transfusion. A Dilation and Curettage (D & C) procedure was undertaken on 29 July 1982. Despite preparation with Cryoprecipitate and Factor VIII before the procedure, the doctors found it difficult to control the bleeding following the procedure, meaning I had a lot of Factor VIII and I had nine units of blood transfused. I was not told about any risks associated with the treatment.

8. I was later informed by Professor Savidge, Director of the Haemophilia Reference Centre at St Thomas' Hospital, by letter dated 20 May 2003 that it was these blood products that I received in 1982 which were contaminated with Hepatitis C, as the batch numbers of the blood I received were consistent with known contaminated blood (Exhibit WITN1026002). I did not have any other blood products between 1982 and my diagnosis with Hepatitis C in 1990.

Monitoring for HIV

9. I had requested my medical records in 24 April 2003 as part of my involvement in the litigation against the American drug companies and they contain a letter from Dr Vaughan Jones, a Consultant Haematologist at St Peter's Hospital, to Dr GRO-B, my GP, dated 15 May 1984 which referred to me being monitored for HIV for a period of 2-3 years (Exhibit WITN1026003). This letter stated that I was given bottles of Factor VIII from the same batch as that which had been on a number of batches of the two known English cases of AIDS in haemophiliacs. Dr Jones confirmed that Haemophilia Centres had been asked to carry out tests at regular intervals for up to four years *"on all such cases without telling them that there is any suggestion that they might catch AIDS."* When this letter was written two years had elapsed since I had received the particular Factor VIII treatment. Dr Jones continued, *"The chance of catching the infection are of the order of one in a thousand and as there is no treatment it didn't seem to me to be ethical to make the approach."* Dr Jones had written to my GP asking him to *"keep an eye"* on my clinical state and to notify Dr Jones if I presented with any illness for which there was an unknown cause.

10. I was never informed that I was being monitored for HIV. I was devastated by this and I believe I should have been told. I felt as though I may have wasted those years of my life. Had I known that I may have contracted HIV and time may have been short, I may have chosen to have lead my life differently.

11. In approximately 1986, I was asked to have a HIV test, which I agreed to. Until then I was not aware of the risk of contracting HIV from contaminated blood products. Afterwards, it stayed on my mind, although the doctors seemed to think that I would not contract HIV; the test was a precaution. I was made to feel by my brother as though I should have been grateful that the doctors had saved my life in 1982, which I was, but they also put me at risk of Hepatitis and HIV.

12. I was tested by Dr Jones. I did not have to wait long for the test results and they were negative. I cannot remember how I was told about the results. Until I had the test results I was worried about what the future held.

Diagnosis with Hepatitis C

13. Dr Jones had recommended a blood test for Hepatitis C to me in 1990, as I had presented to him with symptoms of hot sweats at night, particularly after consuming alcohol, and persistent tiredness. I waited a few weeks for the test results, which were positive.

14. I have seen in my medical records that I received a letter from Dr Jones on 3 January 1990 (Exhibit WITN1026004), which refers to my non-A non-B Hepatitis, although I do not recall being told about this. The letter states:

    "Your serum went to Colindale for testing with the new reagent to detect antibodies were found in your serum so your so-called non-A non-B hepatitis was due to Hepatitis Virus C. In practical terms that doesn't make a great deal of difference!"

15. Although I am not sure when, Dr Jones informed me I had Hepatitis C, Genotype 1A, which I was told was the most difficult to clear. It was described to me as a "*time bomb waiting to go off*". At the time, there was not much information about Hepatitis C. I was aware that I could develop liver disease and cancer, but I did not really know what was going to happen, and neither did Dr Jones. I had to seek information myself. I even got a second opinion from Kings College Hospital

in 1992 [WITN1026005]. At the time, there was a lot of information coming from America, and I contacted The Haemophilia Society for information too.

16. Dr Jones did not inform me of the risks of transmission of Hepatitis C through sexual or blood transmission. He did not recommend a test for my husband. At the time, there was no treatment readily available but Dr Jones suggested there may eventually be treatment or a cure. At first I was not worried as I believed Hepatitis C was the same in terms of severity as Hepatitis A or B.

17. In terms of the information I was provided with, I have seen in my medical records that I saw Dr Tibbs, Kings College Hospital, in August 1992. He stated in a letter dated 26 August 1992 to Dr GRO-B (Exhibit WITN1026006), my GP, that he had spoken to me at length about Hepatitis C and its treatment, and that it affected up to 80% of haemophiliacs in the United Kingdom. He describes in the letter the first treatment option being Interferon, which is given by injection and has *"quite debilitating side effects".* The second treatment option was Ribavirin, which was still in the preliminary stage of evaluation at that time and was an oral treatment. The letter describes that I was happier with the side effects of Interferon, as the effects were short lived, generally over the first month of treatment, and that I was told there was around 25% of treatment being beneficial in the long term. I recall this meeting and this accurately reflects the conversation.

18. I have seen correspondence within my medical records from Robert Hagger to Professor Kamm at St Mark's Hospital dated 15 May 2000 which confirms that I contracted Hepatitis C from contaminated blood products (Exhibit WITN1026007).

Section 3: Other Infections

19. I do not believe I received any other infection, apart from Hepatitis C, from infected blood products. However, there is a reference in my medical records to a sample dated 15 July 1999 which confirms Hepatitis A was detected.

20. Having reviewed my medical records, I am aware that I attended a clinic at St Thomas' Hospital on 9 April 2009. At this appointment I was reassured that I had no higher risk than anybody else of contracting vCJD. I have also seen a letter from Professor Savidge to Dr Bernard (Consultant Haematologist at St Peter's Hospital) dated 22 March 2005 (Exhibit WITN1026008) which confirms *"it is, thus, clear from our records that this patient has never received UK domestic plasma-derived Factor VIII concentrate from this site during the respective timeframe."*

Section 4: Consent

21. I agreed to have blood transfusions and products when I had my son in 1979 and a termination of my pregnancy in 1982, as they saved my life.

22. I did not know that I was being monitored for HIV from 1984, as set out in paragraph 9 above.

23. I was aware of the HIV and Hepatitis C tests being carried out. However. I was never informed about the sample dated 15 July 1999 which confirms Hepatitis A was detected.

Section 5: Impact

Treatment for Hepatitis C - Interferon

24. As mentioned above, I was first informed that treatment with Interferon for Hepatitis C was available in 1992. In my medical records, there is a letter from Dr Hunt, Consultant in Haematology at St Thomas' Hospital to Dr Jones, St Peter's Hospital, dated 19 November 1992 (Exhibit WITN1026009) about treatment. I was aware there were difficulties with obtaining funding and a delay to the start of my treatment. The letter states:

"She thus is a suitable candidate for alpha interferon. Unfortunately alpha interferon has yet to be licensed in this country and therefore no one is willing to

pay for it! The cost of alpha interferon treatment for a year is £3-5000 depending on the dosage… I have tried endlessly but unsuccessfully to obtain funding for this… Apparently the Department of Health are, in view of the pressure from many people, reconsidering licensing it in January. I have actually written to your District Health Authority to ask if they would pay for alpha interferon with chronic Hepatitis C and they have refused… Obviously we have over a hundred patients with chronic Hepatitis C so we just cannot take on the financial burden of treating these patients without funding."

25. However, I have also become aware from my medical records that Dr Jones was considering Interferon treatment earlier than this, in 1990, but decided it should not be pursued. I cannot recall knowing this at the time. In his correspondence to my GP dated 12 December 1990 (Exhibit WITN1026010), he confirmed that my liver function tests were slightly raised, which caused him concern over the years. This letter states that Dr Jones had discussed the option of treatment with Professor Savidge who considered my results were not sufficiently raised at that time as to merit treatment. As a result, Dr Jones decided that treatment was not required.

26. It was not until 1996 that I was offered Interferon treatment for Hepatitis C by St Peter's Hospital. Treatment with Interferon lasted three months. I was not given much information about the treatment. There was not a lot of information available at the time but I recall being told it was estimated there was a 40-50% success rate. I felt it was a chance I had to take. I had to have three injections a week. The nurse came out once to show me how to inject the Interferon. I did not tell my son about the treatment until I knew the results.

27. Prior to the treatment I had felt tired and was frequently out of breath. Everything felt like hard work. I was not told whether these symptoms were as a result of my Hepatitis C.

28. My husband recalls that I had a number of side effects from the Interferon treatment. He recalls I was sick, moody, slept frequently and could not get up, my hair fell out, I had joint aches, and that it was a very rough time. He remembers the effects that the treatment had on me better than I do, I just remember being very tired and having flu like symptoms.

29. I had a Polymerase Chain Reaction ("PCR") test following the three months of treatment to confirm whether the virus had cleared. This test was sent St George's before Christmas 1996, but unfortunately, I was informed that the blood test was lost. I continued taking Interferon for another three months. A second test was sent to Collingdale on 4 March 1997 by courier and I was informed on 21 March 1997 that the virus had not cleared. I had waited seven months to find out whether the Interferon was working or not. I was so disappointed that I had gone through all the side effects for it not to be successful. I wrote a letter to Dr O'Shaughnessy at St Peter's Hospital on 4 April 1997 (Exhibit WITN1026011), once I had been informed the virus had not been cleared, to ask for an appointment to discuss:

- Counselling;
- Being put into contact with other patients with the same virus;
- Having a point of contact at the hospital for extra needles and medication, which would be kept confidential, rather than having to speak with the receptionists;
- Being given more information about the virus including information on prognosis, how advanced the disease was and what to expect in the future;
- GPs being given more information about the virus; and,
- Improving patient's overall experience of the virus.

30. I had the option of continuing on Interferon for another 12 months. Alternatively, I was told there was another drug due to come onto the market with a 20-25% chance of success, but there were increased side effects. I was concerned my

quality of life would be affected by another course of Interferon and so I decided to wait for a new drug.

31. Meanwhile, the virus was active in my body and I thought I was going to die. I was still feeling very tired and out of breath. I was disappointed the Interferon treatment had not worked and I felt very down. I began writing a book to my son, leaving notes to him and my husband telling them that I loved them, and explaining what was happening to me. I did not know what the future would hold but I hoped the next drug would be the cure.

Treatment for Hepatitis C – Interferon and Ribavirin

32. In 2002, I was offered Interferon and Ribavirin combination treatment. I had read that there was a good response rate to this drug, but that it did not work for everybody the first time. I took the combination for two months; I had to inject myself three times per week. It was a horrific drug. I had joint aches, I was tired, my hair fell out, I had pain in my right eye and pressure in my left eye. Before I started this treatment, I was just told I would experience flu like symptoms.

33. Professor Savidge suggested I stopped the treatment as he was unsure about the side effects I was experiencing. I stopped the treatment on 23 April 2002. after two months taking the drugs. I had blood tests, liver function tests and Hepatitis C viral load test but unfortunately these confirmed I had not cleared the virus.

34. Following this treatment I was diagnosed with diabetes. My father had diabetes and so this may have been hereditary, although I am aware that some other people have contracted diabetes and they believed this was due to Interferon and Ribavirin treatment. I read about this, although I cannot recall where. It may have been within information provided by The Haemophilia Society or the Skipton Fund.

35. Again, I did not tell my children I was receiving treatment, particularly as my daughter was taking her GCSE's at the time. I went to bed when the children left the house. I could hardly walk.

36. My liver function was monitored. I had an ultrasound scan every six months and then I would see a consultant. I cannot remember when the scans started but the doctors decided they needed to check my liver regularly. When Fibroscans became available, which is a type of ultrasound to look for inflammation in the liver, I began to have them regularly too.

Treatment for Hepatitis C – Harvoni

37. My liver function tests continued with scans every six months, with a Fibroscan every 12 months. My fibroscan results were as high as 11.8 at one point in March 2014, and so I was put forward for a new drug treatment, Harvoni, by Dr Thompson at St Thomas' Hospital in 2015. Treatment was with a daily tablet for three months and I was told it cost £80,000-£100,000 per patient. I began treatment in May 2016.

38. I was told this drug treatment was more successful and there were fewer side effects than with Interferon and Ribavirin. I did have some side effects; I was tired and very cold; I could not get warm. The side effects of Harvoni were not as bad as Interferon and Ribavirin.

39. A few weeks after treatment was completed in September 2016, I was told that the virus has cleared. Now, I still feel tired and out of breath but it is a relief to know I do not have Hepatitis C any longer. However, it will never erase the memories of over 30 years of having Hepatitis C.

40. Following treatment with Harvoni, I will continue to have Fibroscans every 12 months for three years to see whether anything changes. I also have six monthly ultrasound scans. My liver test results have now reduced to 7. I was supposed to have a Fibroscan in March 2019 but due to staff changes at St Thomas' Hospital,

I am still waiting for my appointment. To date, these scans have only showed a fatty liver; I have not developed lesions.

Impact on Employment

41. I was child minding in 1990 when I was informed I had Hepatitis C. I stopped child minding as I did not want to be accused of putting the children at risk. I made up an excuse to do so, so that I did not have to tell anyone about my diagnosis. At the time there was not much information about Hepatitis C and its transmission.

42. There was a stigma around Hepatitis C at the time but there was not much real information available. When I went to the hospital for treatment in the 1990's, "Hepatitis C" was written in bold across my records. I was frightened to share a glass, toilet seat or toothbrush with anybody. Whenever I accidentally cut myself on something I bleached everything. The Haemophilia Society gave us some information on what to do. I was still frightened though and so I stopped working due to the fear of transmission.

43. I worked in an estate agent on a Saturday in 1999 so that I did not have to give much information out about myself.

44. I was offered a three month trial at KFC working on the office accounts on data processing in around 2004. I was offered the job and one of the benefits was private medical insurance. I had to provide medical information to accept the position and I froze. In the end I did not take the job as I did not want them to know I had Hepatitis C due to fear of the stigma associated with it.

45. It has had a big financial impact on me and my family. My husband's employment provided the only income in the family and I do not have a pension now. This has put additional pressure on my husband. Travel insurance was very expensive for me, as I would always tell them everything, even though I felt my medical history was private.

Psychological Impact

46. The diagnosis and treatments had an impact on my mental health. I had "brain fog" and my diagnosis with Hepatitis C was on my mind all the time. I was always worried I would transmit the virus to somebody else. When I was tested for HIV in 1986, the way the nurses put on their gloves and bleached all the surfaces, made me feel dirty or like a leper. I got the impression at that time that it was really contagious.

47. I used to be an outgoing person but after my diagnosis I did not want to mix with anybody and risk infecting them. I did not make friends. I did not tell my family or friends about the diagnosis. I did tell one friend and her reaction was to go to the doctor to find out if her children could get infected by me. I felt terrible; as if I was some sort of leper.

48. After treatment with Interferon and Ribavirin in 2002, and before my next treatment with Harvoni in 2015, I tried to commit suicide by taking tablets with gin. It was not planned; I took the tablets that were in the house. My husband noticed something was wrong and called an ambulance. I was sick before the ambulance arrived.

49. I thought I had put people at risk. I felt nobody was listening to me and it became too much. I also felt guilty because my family had given me an alcoholic drink at my 60th birthday party and I thought it would skew my liver test results. When I was first diagnosed with Hepatitis C, I did not drink at all, until my 60th birthday party. After that I did not drink for 5 years until I tried to commit suicide in 2015. I recovered in hospital after this incident.

50. When I was told I had cleared the Hepatitis C virus in September 2016, I began to have the occasional glass of wine, but then I had to stop because it affects my diabetes.

Impact on the Family

51. I did not tell my children that I had contracted Hepatitis C until after my daughter's GCSE's. They were very worried about me, however, they did not know much about Hepatitis C at the time, and neither did we.

52. We did not want to tell our children as we did not want it to affect their lives or for them to be treated differently as a result of it. We did not want them to tell other children and for them to be worried about being friends with our children. Children can be spiteful.

Obstacles to treatment

53. Since reviewing my medical records I have become aware that there were some obstacles to me receiving treatment. For example, there were difficulties in getting a qualitative PCR test prior to commencing Interferon in 1996, because local centres were not willing or able to do such a test. St Peter's Hospital was reluctant to commence Interferon treatment without this test so I understand from my medical records this did cause a small delay.

54. In March 2008 I was referred to Dr Finch, a Gastroenterologist at St Peter's Hospital, as I had developed heartburn and acid reflux due to one of my medications. Dr Finch proposed treatment with medication rather than an endoscopy, due to apparent risk of vCJD (although it has been confirmed that I did not receive any UK domestic plasma-derived Factor VIII concentrate, see paragraph 21). In a letter to Dr **GRO-B** my GP, dated 11 March 2008 (Exhibit WITN1026012), he states: *"I do not think it is appropriate to undertake an endoscopy – I note that whilst it is most unlikely, the infusions of blood products that she has received in the past do put her at an increased risk of variant CJD and we would therefore have to discard an endoscope after performing such a procedure (20,000 pounds). This is clearly inappropriate!"*

Section 6: Treatment / Care / Support

55. St Peter's Hospital was my first port of call for emergency treatment, whereas St Thomas' Hospital was my hospital for routine haematology appointments and treatment. In 1982, I was frequently haemorrhaging and needed emergency treatment with blood products at St Peter's Hospital.

56. In the early 1990's I was told I was "draining the blood bank" at St Peter's Hospital which was very costly. I believe St Peter's Hospital was then obtaining blood products from Tooting Hospital blood bank. Thereafter I was sent to St Thomas' Hospital for operations. I believe I was sent to St Thomas' Hospital due to my diagnosis with Hepatitis C and the associated costs.

Psychological support

57. We were not offered any psychological support or counselling until around the start of the Inquiry, when we received a letter from St Thomas' Hospital. We considered this to be a little late as it would have been helpful at the time of my diagnosis and treatment. When I was first diagnosed I had nobody to talk to about it or to speak to about their experiences of living with Hepatitis C. This is why I joined The Haemophilia Society.

58. I was 31 years old when I was diagnosed with Hepatitis C and I was cleared of the virus at 65 years old. It was a long time to have Hepatitis C and to endure the psychological effects of that.

Section 7: Financial Assistance

59. I found out about the Skipton Fund through The Haemophilia Society. I received the second stage payment of £20,000 on 18 August 2004. I also received another payment of £25,000 on 27 June 2005 and £25,000 on 20 April 2011. I then began receiving staged monthly payments. The money helped a great deal, but no

amount of money can pay for the things that we had to endure, which were no fault of our own.

Stage 2 payment

60. I understand that to be eligible for a Stage 2 Skipton Fund payment, the disease must have progressed to affect your liver, for example, progression to liver cirrhosis or liver cancer. I have seen in my medical records in May 2004 that the doctors considered I had early cirrhosis as a result of Hepatitis C [WITN1026013]. I have also seen in my medical records that my fibroscan results began to increase in 2013, meaning my liver was progressively deteriorating. In a letter from Dr Wong to my GP dated 25 September 2013, it states: *"I have also explained to* **GRO-B** *that with the deterioration of fibroscan that there is a likelihood that her hepatitis C will progress to liver cirrhosis"* [WITN1026014]. Then in March 2014, my fibroscan result increased to 11.8 kPa [WITN1026015], which I understand indicates I had liver cirrhosis, it being a result higher than 11.5kPa [WITN1026016]. The reading may have slightly changed since.

61. Professor Savidge completed the forms for the Skipton Fund Stage 2 payment based on the medical information he had available at the time. Professor Savidge confirmed in the Skipton Fund forms that I could not have a liver biopsy as I had Von Willebrand's disease. I did not find the application process difficult, as Professor Savidge dealt with the paperwork. I received the Stage 2 payment from the Skipton Fund in 27 June 2005.

62. I feel very guilty that some people who are worse than me, are not getting as much financial assistance as me. I consider I do not deserve the money from the Skipton Fund. This has led me to believe that I am being followed and photographed by people who do not think I should be receiving financial assistance from the NHS.

63. I saw a psychiatrist to help me to deal with this guilt in approximately 2012. I saw a private psychiatrist initially, as I did not trust the NHS. I did later see an NHS psychiatrist after 2014 and I was given medication. I have not had psychiatric treatment since 2018.

Section 8: Other Issues

64. I was involved in the group litigation against the American drug companies in around 2003, which I found out about through The Haemophilia Society. I instructed Michelmores LLP in Exeter in that litigation on a no-win no-fee basis. I obtained my medical records for this litigation in 2003, which was fortunate as I recently requested my medical records from St Thomas' Hospital and they confirmed they did not have any records prior to 2009. I received approximately £9,000 USD on 9 November 2010, following this litigation.

65. All the years of having Hepatitis C have changed my life. It is difficult to think what maybe I could have done had I not contracted Hepatitis C. I did not work as I did not think there was a point in retraining for a different role and I did not want to have to disclose the fact that I had Hepatitis C to an employer. I spent more time at home with my family as I did not know when or if I would die, or how the drugs would affect me.

Statement of Truth

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

Signed GRO-B ....

Dated....14-10-19...