Witness Name: GRO-B
Statement No: WITN5606001
Exhibits: WITN5606002 - WITN5606008
Dated: 06 June, 2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006, dated 02 August 2021.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1940. I reside at GRO-B. I married my husband GRO-B in GRO-B we did not have any children. Sadly, my husband passed away in 2002, on GRO-B I am currently retired, having formerly worked as a Chartered Librarian in Colleges and Industry.

2. I intend to speak about my infection with Hepatitis C ("HCV") after I received multiple blood transfusions at the Edinburgh Royal Infirmary in July 1978 following a horse-riding accident. In particular, the nature of how I learnt about my infection, how my illness has affected me and my husband and our lives together thereafter, also the financial assistance I have received.

3. I can confirm that I have chosen not to have legal representation and that the Inquiry Investigator has explained the anonymity process to me. I confirm that I do not wish to be anonymous as I wish for my story to be known in full.

4. The Inquiry Investigator has explained to me the 'Right to Reply' procedure, and I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.

5. I wish to acknowledge that naturally as time passes, memories can fade. I have been able to provide approximate time frames for matters based on life events. However, these time frames should be accepted as 'near to' rather than precise dates in some instances where I have been unable to recall the exact dates.

6. I have constructed this witness statement with access to my medical records.

Section 2. How Infected

7. My family lived in Kent but because of the bombing my mother was removed to a nursing home in GRO-B Buckinghamshire where I was born on GRO-B GRO-B 1940. When I was four years old, my family moved to Lancashire where I grew up. Then, in 1969 when I was in my late twenties, I moved to Edinburgh to pursue a career as a Chartered Librarian, having previously trained in Manchester. Prior to this career change, I was training as a hospital laboratory technician, but for family reasons I had to give this up to help with the family business.

8. In the spring of 1976, I met my husband GRO-B in Edinburgh. I was not going in search of 'Mr right', but he just arrived in my view. He was a GRO-B man with Scottish and Welsh heritage. Within the same year of our meeting, GRO-B and I got married on GRO-B

9. At the time of my marriage, I was working in the Library of the GRO-B GRO-B premises, GRO-B We decided I should take some time

off to enjoy being a housewife, although I did get called in to do occasional relief work before my accident.

10. On 05 July 1978, I was out with a group horse riding when I fell off. My foot caught in the stirrup so I was dragged along for a short while before the stirrup broke off. Scarring on my back would have been my only injury but the horse stood on me twice. Apparently, I was rolling around in the mud but I can remember that I was drifting in and out of consciousness. During one brief period of consciousness, I opened my eyes and found I could not see. I said that I was blind and had ruined our marriage. The next time I came round I could see. Later, I found it to be like a Paul on the road to Damascus experience (and it did have the same effect!)

11. An ambulance had been called following my accident. While on the journey, my last memory is saying that my feet were very cold! I was taken to the Accident and Emergency Department at the Edinburgh Royal Infirmary which was then situated near to the centre of the city.

12. Obviously, I cannot recall the exact details surrounding the time of events, but I had subsequently been told by one of the sisters at the Edinburgh Royal Infirmary that when I was admitted to the Accident and Emergency Department, I was conscious and responding to speech. I have no recollection of arriving at the hospital. However, I had soon gone downhill with regards to my health. I thought I had just arrested, but I was told that I had died and I was brought back to life. I can recommend internal bleeding as the perfect way to slip away!!

13. I had the right people around me at the right time who were able to save my life through resuscitation. I am very grateful to put it mildly! Within my medical records, there is a report which states that I was resuscitated. I was also told at some point that as I was being rushed along a corridor, surgeons were falling in behind my 'trolley', There were five of them, two wanted me to be allowed to slip away but three knew of a recently successful operation on a young welsh man who had had his liver crushed in a car accident.

14. Shortly after arriving at the Edinburgh Royal Infirmary, I was transferred to the operating theatre to undergo an emergency laparotomy, due to having sustained a partial hepatectomy caused by the trauma to my liver caused by the fall.

15. After the operation, GRO-B old me that there were medics all around the bed. I took hold of GRO-B s hand and I had started to write the word "*sorry*" on GRO-B s hand with my finger, and he could not make it out, so one of the nurses had told GRO-B "*she is writing the word sorry.*" GRO-B told me that after that all the medics left the room. My assumption is that this showed the medical staff that I was cognitive as they had thought that I may have sustained brain damage due to the lack of oxygen when I was unresponsive.

16. During the operation, the surgeons had cut me across the abdomen and I was bleeding profusely. A page within my medical notes describes it as blood flowing freely from my abdomen. Due to the blood I had lost as a result of my ruptured liver, I was given a blood transfusion of ten units of blood, vitamin K and platelets.

17. A Medical Report, dated 12 January 1979, from the Edinburgh Royal Infirmary (exhibited at **WITN5606002**), outlines the medical treatment I received at the Edinburgh Royal Infirmary and the blood given as treatment.

18. The report states that I was admitted on 5 July 1978, having sustained abdominal injuries, my blood pressure was 'unrecordable' and that I rapidly became 'unrousable' with fixed and dilated pupils. I was transferred to the operating theatre without any 'detectable peripheral circulation' or detectable heartbeat. An immediate laparotomy was carried out and rapid transfusion undertaken. On opening the peritoneum massive quantities of free blood poured out from a massive trauma to the left lobe of my liver. I was given 'approximately 10 units of blood or blood equivalent', following which I was transferred to Intensive Care Unit (ICU) where I was ventilated. After my operation large quantities of blood were drained and I was then transferred back to the operating theatre the following day where they found, 'fairly vigorous

bleeding from the fat and a general ooze from the raw edge of the divided liver.' They controlled the bleeding with sutures and diathermy

19. After the operation, I was transferred to the Intensive Care Unit at the Edinburgh Royal Infirmary. Thereafter, one of the medical staff at the Edinburgh Royal Infirmary telephoned GRO-B who was at home at the time in the early hours of the morning of 06 July 1978. He was told that my wound was weeping and that I needed to undergo surgery and was asked whether he could give his permission for me to return to the operating theatre. GRO-B hen asked when would this be? to which he was told that I had already been taken down to the theatre to undergo surgery.

20. Due to the blood loss, I had received large quantities of blood. I am unaware as fact how much blood I had received, but as outlined within my Skipton Fund application completed by Professor Bassendine, I had received one hundred units of blood in total and my medical record states that increasing quantities of blood being administered.

21. After the surgery had been completed, due to the injury I had sustained, according to my records I have discovered that Dr Davies ordered a platelet transfusion as treatment. I continued to receive daily platelet transfusions until 11 July 1978, when test results had shown that the level of blood platelets in my body had risen.

22. My progression remained satisfactory following my second operation, so I was transferred from the Intensive Care Unit to a ward on 27 July 1978. When I was first moved from the intensive care to a regular ward, I am assuming that I was being withdrawn from some medications because GRO-B said I was on an embarrassing high which had concerned him. I guess he was concerned that it was a defect resulting from all that had happened to me. He mentioned this to the sister. Their conversation concluded with GRO-B saying "would you employ her!?" As a consequence, I was given a brain scan during which I took a lot of interest causing the staff member to question why I was needing the scan.

23. I had become very attached to a lovely elderly lady that I met on the ward, and when she died following a fall on the ward, I was deeply affected. Although I was told that I was not yet out of the woods, it was thought better for me to be at home. Thereafter, on 02 August 1978, I was discharged home to recover.

24. However, on 06 August 1978, I was readmitted to the Edinburgh Royal Infirmary due to an attack of vomiting and an apparent infection of my abdominal operation wound. investigations failed to show any sepsis apart from a wound infection.

25. After arrangements were made again to continue daily dressings at home, I was discharged from hospital on 04 September 1978.

26. I recall that during my stay in Edinburgh Royal Infirmary, I was asked how much alcohol I drank. I didn't, but whenever I had a cold GRO-B created a concoction of lemon honey and whisky. In those days, I contracted colds easily which always turned to bronchitis. I tried to make an estimation but when I told GRO-B he roared with laughter at my high figure.

27. I also remember that for a few days, the ward sister started to administer sherry to me. It was soon withdrawn when it was obvious that it was objectionable to me. In offering this statement, things I have not given thought to again have come to mind, as happens. At the time, I now recall that I suspected they were testing me. I can remember being insulted because I had been under their care for long enough for them to know that from day one, I showed no indication of being alcohol addicted.

28. Another incident, which even after all this time of having buried it, as I recall it now, brings back an emotional reaction. Not long before I was finally discharged from hospital in September 1978, I was interviewed by a most obnoxious female who consistently bullied me into trying to say that alcohol was an issue in my life. When one has been in hospital for all those weeks it is easy to become institutionalised and I felt very vulnerable. On telling my ward sister, she said that that person was not the right one for the job.

29. I also recall that when I went into hospital, one of my front teeth had quite a story to tell! It had been replaced by a false one held in position – How? My memory fails me. Of course, before an operation they remove false teeth but kept mine for me. GRO-B got in touch with our super dentist. He said there was no problem in reinstating my tooth's fixture. He said he would have come in to see me about it but he was off to Canada.

30. One day after that, I was taken off in a wheelchair to see who turned out to be the hospital dentist. I explained the situation with my own dentist but he said that I had come into hospital with a front tooth and I would go out with one. Again, dealing with someone in a vulnerable state without fight. He removed what would have allowed my dentist to reinstate my tooth without a plate and gave me a plate. That really did upset me and our dentist.

31. After I was discharged from the Edinburgh Royal Infirmary, I attended as an outpatient for regular check-ups when a nurse took blood samples from me and I don't know whether this was for my benefit or theirs. During a conversation, I had asked the nurse what happened to my blood, and I was told that it was sent all over the world including China.

32. At some point, I had been diagnosed as having contracted Non-A Non-B Hepatitis but I am unable to specify exactly when this was and I cannot recall my reaction at the time. I certainly didn't understand the full implications at the time. However, that must have been before I asked the nurse what happened to my blood as I must have been aware that there was something wrong with my blood. She said that they were discovering other types of serious hepatitis at that time including hepatitis G.

33. At this time, I was seeing Mr Jenkins for my check-ups and he commented that the blood I had received had come from a man who was infected in the Borders amongst others, which to my mind meant that they must have been testing the blood before giving it, in order to know that it was not hepatitis A or B therefore it was infected and blood and should not have been used for transfusions. However, in my case, I had exhausted the blood supply and people were called in 'off the street'. I also needed one component of the blood; so if it saved my

life, in hindsight I understand. Non-A Non-B diagnosis pre-dated the discovery of Hepatitis C (HCV). Later on, I was diagnosed with Hepatitis C as stated in a medical letter from 2018, I had HCV genotype 1a.

34. Upon inspecting a letter dated 06 March 1979, from Dr N Finlayson, Gastrointestinal and Liver Service, Edinburgh Royal Infirmary, to Dr Jenkins, (exhibited at **WITN5606003)** it demonstrates that in March 1979, Dr Jenkins had made note of a possibility that I had a chronic viral infection, of which, he had ruled out the B virus. Reference to the 'B virus' is most likely referring to Hepatitis B ("HBV"), which demonstrates that they were testing for a viral infection.

35. Albeit, the quality of the letter is partial, of what is decipherable, the letter states the following:

> *"My examination has not revealed any significant reason why Mrs* GRO-B *should be continuing to have abnormalities of liver function following her hepatic resection. In particular, noted that you have discovered that she has had a consistently raised serum transaminase activity. Obviously, the possibilities arise of some chronic viral infection and I know by that you have excluded the possibility that this might be due to the B virus…"*
> **WITN5606003**

36. In the 1980s, I had tried to determine the cause of my HCV infection. I decided to ask a nurse at the Edinburgh Royal Infirmary where she thought that I had contracted HCV. She told me that she believed that the source of my infection was attributable to a blood transfusion I had received in July 1978, at the Edinburgh Royal Infirmary. They had told me that due to the amount of blood lost, I had exhausted the blood supply at the Edinburgh Royal Infirmary and they needed platelets. They needed an emergency blood supply, so as I mentioned above, they had to turn to the streets as a source of blood, whereby 109 people donated blood so that they could receive sufficient platelets. They wanted the platelets as my blood was not clotting. It was some of those individuals who had donated blood in that instance, who had been infected with HCV.

37. Later, I discovered that those doners were being told that the blood was for a woman who had had a horse-riding accident. One of those doners, all to whom I owe my gratitude, was one of my husband [redacted]s, colleagues and another was the daughter of a friend. He told me, when I was back in circulation, "you've got good Scottish blood now!

38. The aforementioned is outlined in a letter I had written to the Infected Blood Inquiry on 13 May 2018, in reply to an undated letter of July 2017, (exhibited below, at **WITN5606004**). A paragraph of the letter states the following:

> *"I contracted Hepatitis C at the Edinburgh Royal Infirmary on 5 July, 1978 following a blood transfusion, this involved the blood taken from 109 people (so I was told), in order to extract the platelets. Most of these donors were called into the hospital in this emergency…My concern is that at the time I was told I had Hepatitis NON-A NON-B and that some of those who had generously donated blood to me have been identified as having been so infected."*

39. After my HCV diagnosis, my husband and I moved to a village in Cumbria in 1980. Despite being located in Cumbria, I continued to attend Edinburgh Royal Infirmary to see Mr Finlayson - Consultant Physician, for check-up appointments. He wanted me to stay under his care at this time, this involved a 200-mile round trip. I was not receiving any treatment at this time. I continued to see him into the 1980s.

40. On one occasion when I attended an appointment at the Edinburgh Royal Infirmary with my Consultant, Mr Finlayson, I was told that I did not need to attend any more because he said that my virus had "burnt itself out". Obviously, I was very pleased at this news but I have no recollection of having ever been told at that time how serious it was nor did I have an understanding of the implications. It was not until the media began reporting about people dying from it and that they had developed a test for Hepatitis C as opposed to Non-A Non-B, that I realised how serious it was, but I still didn't panic because I felt well.

41. At this point, I felt very cross for all the victims who went on to receive contaminated blood because it was now clearly known that blood was infected with something else other than Hepatitis A or B.

42. I was discharged from the Edinburgh Royal Infirmary in the early 1980s because I was told that I was completely clear of the virus.

43. In the early 1990s I attended a regular 'well woman' check-up at my doctor's surgery, the GRO-B with a nurse named GRO-B who was originally from America and who had become a friend of mine. Mysteriously, a thought came into my head to ask whether they had taken enough blood in order to do a liver function test ("LFT") for me. I was interested in my health, and I knew about LFTs as I had previously trained to be a laboratory technician before I had a career change. My knowledge enabled me to know that I could ask for an LFT, and I am very grateful that I did ask.

44. When the results of the LFT were returned, I was told that my HCV had not in fact cleared, but that I still had HCV. My nurse friend was more upset than I was but then she knew the significance. I have to trust that I was clear but then HCV returned at some point, but I'll never know. If I had continued to be monitored occasionally, it would have been detected when it had returned and maybe I could have avoided cirrhosis, but then why would they monitor me if they believed that I had cleared the virus I suppose I am just so grateful for the years of life the transfusions afforded me, that I didn't dwell on it.

45. As a result of the virus still being detectable, I was placed under the care of the Cumberland Infirmary, Carlisle, however, within a short period of time, I was then transferred to the care of the Freeman Hospital ("Freeman"), Liver clinic in Newcastle upon Tyne. In my view, the Freeman is a wonderful hospital.

Section 3. Other Infections.

46. I do not believe that I have received any other infections, other than HCV as a result of receiving contaminated blood during transfusion in 1978.

Section 4. Consent

47. I do not believe that I have been tested or treated without my prior consent having been obtained, or without my knowledge, consent, or for the purposes of research. However, historic medical records would appear to imply that they had tested for viral infection as far back as 1979, because B virus is mentioned in that document. (**WITN5606003**)

48. When I received the blood transfusion during my surgery on 05 July 1978 at Edinburgh Royal Infirmary, this was administered during a surgical operation in theater, in an emergency situation. I was unable to provide consent as a result, but I believe that the medical profession did what was necessary in the circumstances to save my life.

49. When I had gone into theatre on 06 July 1978 for the second time, GRO-B had consented to the operation having taken place on my behalf, as mentioned previously.

Section 5. Impact.

Mental/Physical Impact

50. I believe that my HCV infection has had a range of effects on my physical health.

51. Following my HCV diagnosis in the 1990s, I underwent regular Fibroscans at the Freeman Hospital every three months, but I am unable to recall the exact time frame for this. At some point, I was told that I had developed scarring of the liver and I was diagnosed with cirrhosis. I was put on a clinical trial for treatment.

52. I had also undergone two endoscopies at the Freeman, as the medical profession were worried that ulcers could develop on my stomach. When the results had returned, I was told that ulcers had not developed.

53. I previously underwent two invasive liver biopsies, whereby a small piece of liver tissue is removed to examine for signs of damage or disease. The first of my liver biopsies took place at Edinburgh Royal Infirmary as far as I recall, and the second biopsy definitely took place at the Freeman in 1995.

54. I received the result back from the liver biopsy quickly. I cannot recall how I was notified; whether this was in person, via telephone, or contained within a letter. I was told that the results of the biopsy had shown that I had developed cirrhosis of the liver.

55. I have seen a report within my records from 2012, that it was suspected that I had an element of Portal Hypertension. I made no more enquiries about this and I didn't fully understand or follow it through, but as it came from the Liver Clinic, I assumed it was something to do with my liver and my understanding is that the most common cause has been shown to be cirrhosis of the liver.

56. To date, I take medication for my underactive thyroid function which I was diagnosed with whilst in hospital undergoing my second liver biopsy. They discovered it through my very slow pulse. I am not sure if this is connected to my HCV?

57. Since my original operation in 1978, I have developed a suppressed appetite as I no longer get hungry. I also discovered I was unable to digest meat due to the pain and I worked out it was meat by a process of elimination.

58. From the point of my transfusions until my HCV diagnosis, I was terribly fatigued and tired. I had previously attributed this to having recovered from a terrible accident, but it has been shown to be attributable to the effects of HCV on the body. I recall that when I mentioned this to Dr Finlayson, he was very dismissive as though I was a malingerer.

59. I also developed issues with hair loss and my nails. I recall a Consultant Mr Jenkins at Edinburgh Royal Infirmary used to hold my hands and seriously examine my nails and stare at them, with no comment during the consultation. I assume that there must have been a connection between the look of my nails and the hepatitis. I don't remember having any trouble with my nails before.

60. I am unclear as to whether the aforementioned conditions of my nails and hair that I have experienced are associated with the HCV infection or the clinical trial for HCV. With regards to my hair loss, I did lose hair during the long weeks in hospital which was mainly around the crown of my head. I also lost hair when I was on the clinical trial. My hair grew back and recovered however my nails have never recovered and constantly split.

61. Within the last year, I have noticed that I have developed a distended tummy. without having put on any weight which I will be mentioning to my GP.

Treatment

62. As mentioned previously, with my agreement I was offered and put on a clinical trial for treatment to clear my HCV by Mr Jones, (who is now a professor) a Consultant at the Freeman Hospital then. I was told that it was part of what was clinical trial, whereby I would take a combination of Interferon and Ribavirin. I cannot recall how long the treatment lasted.

63. I started on this clinical trial in 1997. I administered Interferon by injection and Ribavirin in tablet form. I responded negatively very quickly. At the end of the trial, I was clear but had to wait an amount of time for the last test to confirm that I was definitely clear. Mr Jones said that because I had a healthy lifestyle and had never smoked or drunk alcohol and because I had responded well to the clinical trial, there was only a 1% chance of it returning. Unfortunately, when I attended the clinic to get the last test result, I learnt that my HCV infection had returned. I was told that it was a 'vicious little virus'.

64. My treatment impacted our lives because I felt terribly ill and could not stand for long. My husband was an absolute gem in his help and caring of me. Through

this time, his social life and commitments were also affected. Plus, we had to do the regular 120-mile round drive from GRO-B to the Freeman hospital.

65. I was not offered a further course of treatment at the time but I kept attending regular check-up clinics. These involved mostly ultrasound and a visit to the clinic where they took blood. During that period, I had two endoscopies.

66. At the end of 2015, I attended a face-to-face consultation with Dr Stuart McPherson, Consultant Hepatologist at the Freeman, whereby I was offered a course of treatment with Harvoni and Ribavirin. A letter within my medical notes states that I would be a suitable candidate for treatment in a couple of years when new treatments had been developed. I was told that this time it wasn't a trial but a cure.

67. This information is contained within a letter, dated 14 December 2015, from Dr John Jacob, Gastroenterology, and Dr Stuart McPherson, Consultant Hepatologist at The Freeman Hospital, sent to Dr GRO-B GRO-B (exhibited as **WITN5606005**). The letter states the following:

"***Diagnosis:*** *Post transfusion chronic hepatitis C genotype 1a*
Previous responder/relapser to combination antiviral therapy – 1997/98
Cirrhosis – Childs Pugh A
Autoimmune hypothyroidism

Obviously GRO-B is aware of the potential new treatment regimes in viral hepatitis C which are much better tolerated than the previous treatments that she embarked on almost 2 decades ago. We discussed today the new all-oral DAAs and that she would potentially be a candidate for Harvoni. GRO-B was initially a little reluctant about this as she remembers some severe side effects from her previous treatment but I have explained that the viral response rates are much better and the adverse events many fewer than previously. She is willing to be discussed at the Viral MDTM."
WITN5606005

68. On 15 February 2016, I commenced my course of treatment with Harvoni and Ribavirin, which was projected to last for a period of around twelve weeks. I

administered Harvoni (Sofosbuvir 400mg/Ledipasvir 90mg) once daily in tablet form, and Ribavirin (600mg mane/400g nocte) again once daily in tablet form.

69. Before commencing the treatment, I was informed of the possible associated side effects. This included fatigue, headaches, pruritis and very occasionally jaundice. Whilst I did feel tired, lethargic and a bit grotty, I did not feel as bad as I did with my first course of treatment. This was great news as unfortunately, I no longer had my husband GRO-B with me to help as I went through my course of treatment.

70. At the end of the twelve-week course of treatment, I was hopeful that this treatment had been more effective in clearing my HCV. I knew from previous experience that HCV was a vicious little virus which could come back. Fortunately, on 01 November 2017, I was given the all clear at clinic. On receiving this news my reaction to myself was to be cynical due to my past experience, my pessimism proved to be unjustified.

Impact

71. I believe that my HCV infection had an impact on my husband GRO-B He had to look after me throughout my first course of treatment in 1997/1998, as I was not well enough. I know that he was very pleased when I was transferred to the Freeman for my care, as he knew it was the best hospital in the north, in our opinion.

72. I cannot say that I have experienced any stigma associated with my HCV diagnosis. I was not warned about any stigma associated with HCV by the medical profession, so I was, and have always been very open with people about my HCV infection until I found out there was a stigma attached. I had a virus that I had contracted through no fault of my own, (except for being stupid enough to fall off a horse!) so had not occurred to me.

73. Not appreciating the stigma associated with HCV at the time, I told people in my village. I live in a small community and with hindsight, I wonder what was, and is, said about it behind my back.

74. For a number of years, I used to attend a local school to read with the children voluntarily. I had asked Professor Bassendine whether I should tell the headmistress at the school about my HCV, but I was told that this was not necessary and that I shouldn't mention it. That was when I realised there was stigma attached.

75. My first HCV diagnosis did not have a work-related effect on me as I was not working at the time of my diagnosis, as I had become a housewife. However, once we were living in Cumbria, I did cover for maternity leave in schools and I also did a mixture of voluntary and paid relief work at a day centre for lovely adults with learning difficulties.

76. I knew that I couldn't have maintained a full-time job given how tired I was. This was during the mid 1980s also the 1990s, when I had been re-diagnosed. Also, some of this time I was a governor at our local primary school. When I was relief-working I gave my all, however, when I returned home, I was exhausted and knew I couldn't sustain a full-time job. However, I never claimed any sickness benefits.

Section 6. Treatment/Care/Support

77. As far as I can recall, I was not provided with information on the risks to others being infected as a result of my HCV. As far as any information surrounding the nature of my infection, I think I did pick up leaflets at the Freeman hospital.

78. My husband was not ever offered a blood test to test for the presence HCV. In 1994, I instigated him having a test for HCV as we were going to South Africa and I would not make the journey until I was sure that he had not caught HCV

from me. When the result returned negative this gave me peace of mind and proved to me that it had to be transmitted blood to blood.

79. I have no memory of having been provided with any comprehensive information which would have allowed me to adequately understand or manage my infection. However, I was referred to a dietician due to weight loss and I was encouraged to eat vegetables with plenty of iron. All the nurse kept saying was, that I needed to admit that I had the virus. I can recall them saying something along the lines of. "*you can die from it you know? It is terminal.*" I did not want this applied to me. I did not want to admit to having HCV, as if I admitted to it, my brain knew I had it. I carried on not dwelling on it. I don't expect anyone to understand my philosophy!

80. I would like to add that I had every confidence in the team at the Freeman Hospital and was very happy with the care I was given.

81. I believe that I was told as soon as the medical profession had become aware of my HCV. However, with hindsight, it should have been as soon as they were testing people and finding that they were infected with Non-A, Non-B, then it was obvious that it should have stopped being given to people, that way they could have eliminated all these hundreds of people that have got HIV and HCV or further discovered hepatitis.

82. I believe that I may have faced some difficulties in obtaining treatment, care and support in consequence of being infected with HCV. In particular, this relates to two incidents.

83. Firstly, as previously outlined above, I had been told in the 1980s by a medical professional at the Edinburgh Royal Infirmary that I had cleared my Non-A Non-B hepatitis infection. However, some years later after having asked for an LFT, in the early 1990s, the result of this test came back positive for HCV. I find it hard to believe that the medics at the Edinburgh Royal Infirmary would get it wrong, That was when they had developed the test specifically for Hepatitis C, but it was known long before that that blood was showing up with a hepatitis

that was not A or B, so should not have been used for transfusion for as long as it was.

84. From 1984 to the time of it being in the media in 1991, I understood that I was clear of the virus because I had been discharged from Edinburgh. Perhaps in hindsight, I should have continued to have blood tests knowing what a vicious virus it was.

85. Sometime during 1991 when I asked for the liver test, the virus had come back. I want to believe that it was indeed previously cleared. As I had no symptoms, I had no cause to question whether the virus had returned. At what point in those 7 years where I was not being monitored, did I get the virus back?

86. I did feel that the consultant was more interested in the virus from a research point of view and not in me as a patient. He told me that he had used me as a case study in various lectures and papers.

87. I do question that if I had continued to be monitored for my hepatitis, I may not have consequently developed cirrhosis of the liver.

88. My views with regards to being told that I had cleared my HCV is contained within a letter I had written to the Infected Blood Inquiry on 13 May 2018, following a letter dated July 2017, (exhibited at **WITN5606004**). The letter states the following:

> *"In 1980 we moved to Cumbria but I continued to go to Edinburgh Royal Infirmary for checks until sometime in the early 80s I was told that the virus had "burnt itself out." In the early 90s I was having a regular 'well woman' check-up at my Doctor's clinic when mysteriously a thought came into my head to ask if they could also do a liver function test for me. The results came back that I had Hep C. I do not wish to incriminate the wonderful ERH but I do question that if I had continued to be monitored, I may not have consequently got cirrhosis of the liver. (alcohol has never been pleasing to my taste buds) when it was discovered that I still had the virus I have been wonderfully monitored, very regularly, by*

the Liver Department at the Freeman Hospital, Newcastle. However, if I had been saved from getting Hep Non-A Non-B it would have saved much inconvenience of travelling from GRO-B *to Newcastle (for which we made no claim) but more importantly saved the NHS much expense."*

89. Secondly, after my Non-A Non-B Hepatitis diagnosis following my horse riding accident in 1978, I was talking to one of my neighbours who happened to be a nurse in the who had worked at the Edinburgh Royal Infirmary in the haematology department. During conversation, she had told me that I should have seen what was written about me in the 1978 Annual Report of the Haematology Department of the Edinburgh Royal Infirmary. In that instance, I could tell that she had realised what she had said, and that she had told me too much information whereby she completely clamped up. My curiosity has remained to this date and I have wondered what is mentioned about me in the Annual Report. Apparently, the surgeon who had undertaken my surgery in 1978 had named me in reports and lectures, he in fact told me that himself. For what purpose, I am not aware. I would very much like to see a copy of this report.

90. Whilst the Freeman is an excellent hospital, 60 miles each way, to attend a clinic was demanding and particularly treacherous in winter. Sadly, these trips were also added to by those for my darling husband's health problem. After a further two heart attacks over the years, he had a quadrigal bypass operation at the Freeman in December 1988 when, through my voluntary involvement with the GRO-B I should have been with the team GRO-B GRO-B I was not there, much to the hurtful disgust of our leader, because that was when GRO-B was on the operating table, but she did not think that I should have put GRO-B first. There were plenty of my colleagues there and I do not think my anxious state would have helped but she added to it!

91. I do not believe that my HCV infection has had an effect on the dental care I have received. Once I had become aware that HCV could be infectious, I had told my dentist that I had it. They did not treat me any differently thereafter. I was very careful when I attended the dentist, or at the clinic for a nurse to take

blood, if they were not wearing gloves, I used to tell them off. However, I was not told by the medical profession that I had to self-declare my infection but I did this of my own volition.

92. I was not offered any counselling or psychological support as a result of my HCV diagnosis. In the 1970s, they did not make a fuss, it was not commonplace for counselling to be offered. I was not offered it when it was discovered the infection had reappeared, however, this was not something I had given any thought to and it was not an issue for me.

Section 7. Financial Assistance

93. In 2007, Professor Bassendine, Consultant Hepatologist and Professor of Hepatology at the Freeman Hospital, had told me that the Skipton Fund were offering financial assistance to people who had contracted HCV from contaminated blood. She had told me that I should make an application so that I could obtain financial security for my future. I reluctantly applied as I know that nursing homes are getting expensive, and if I have to go into a home in the future, I have the means to pay for it.

94. Professor Bassendine, had applied to the Skipton Fund on my behalf and my application form was received by the Skipton Fund on 21 May 2007. On 13 June 2007, I received the First Stage ex-gratia payment from the Skipton Fund of £20,000.

95. At the beginning of 2010, Professor Bassendine encouraged me to apply for the Stage Two ex-gratia payment from the Skipton Fund due to my cirrhosis of the liver. So, I made an application to the Skipton Fund.

96. The prevalence of the cirrhosis of my liver, and Professor Bassendine's belief that I would be eligible for the Stage Two Payment from the Skipton Fund is outlined within a letter, dated 26 April 2007, from Professor M Bassendine, Consultant Hepatologist and Professor of Hepatology, The Freeman Hospital,

to Dr GRO-B (exhibited as **WITN5606006**). The letter states the following:

> *"I reviewed this 66 year old lady in the clinic in April. She remains clinically well with normal LFT's apart from an elevated ALT of 72 and AST of 56.*
>
> *As you know we undertake surveillance for HCC in individuals with established cirrhosis, which was indicated on her liver biopsy in 1995 (necroinflammatory grade 5, fibrosis stage 4 out of 4). Liver ultrasound at this visit showed the left lobe of her liver is small but parenchyma in the right lobe appears normal, no focal lesions were seen and mild splenomegaly persists. She has a platelet count of 90,000 consistent with hypersplenism.*
>
> *As you know individuals infected with hepatitis C as a result of NHS treatment pre-1991 are eligible for ex-gratia payment administered by the Skipton Fund. Mrs* GRO-B *has provided me with documentary evidence of her multiple transfusions when she fell from her horse and the horse trod on her abdomen resulting in a traumatic transaction of the left lobe of the liver and ruptured liver. I have therefore completed the application form for the 1st stage ex-gratia payment. As she has documented cirrhosis on liver biopsy she will then be eligible for the 2nd stage of payment."*

97. On 25 February 2010, I received a letter from Nicholas Fish, Scheme Administrator at the Skipton Fund, which outlined that my application for the Stage Two Payment had been deferred. This was due to the application providing a number of fairly complex means of determining whether effect of the HCV infection had reached a stage, or 'trigger point' at which the Skipton Fund permits payment. My application had been deferred until a decision had been reached.

98. On 29 June 2010, I received a letter from Nicholas Fish, Scheme Administrator at the Skipton Fund. The letter outlined that they had returned my application for financial assistance under Stage Two Payments, pending more up to date test results to determine the extent of damage to my liver from my doctor, as there was no solid evidence of my liver cirrhosis. They also said that the information supplied by Dr Sheridan had suggested that cirrhosis was not present.

99. I was upset about the nature of Skipton Fund's reply. For someone who had been encouraged to apply for compensation looking ahead for any care I may come to need, it made me feel that I was being viewed as a scrounger.

100. I had written a letter back to the Skipton Fund outlining my views on their decision. The letter states as follows:

> *"Thank you for your speedy reply to my application form. My medics have encouraged me to take this payment because my means will not cover my care needs should I have to be looked after. If I don't need it for that purpose, my ambition is to keep this money to go back to liver research (in my will). I hate this 'take no blame suing society.' The National Health have spent a lot on me and given me 29 years of life that I would not have had if I had not had the blood transfusion. I do appreciate the peace of mind you are giving me and I hope you understand my attitude is not from ingratitude. With every last wish."*

101. It is possible that the Skipton Fund had misinterpreted my application. As exhibited in a letter dated 28 May 2010, from Dr Debasish Das, Specialist Registrar in Gastroenterology/Liver written on behalf of Professor Bassendine, Consultant Hepatologist and Professor of Hepatology at The Freeman Hospital, to Dr GRO-B exhibited as **WITN5606007),** it states the following:

> *"**Diagnosis**: Post transfusion hepatitis C (genotype 1a)*

> *Previous responder/relapser to combination antiviral therapy 1997-98*
> *Autoimmune hypothyroidism on replacement*
> *Liver biopsy 1995 – early micronodular cirrhosis features consistent with chronic hepatitis secondary to hepatitis C infection.*
>
> *I reviewed this lady in clinic today. I am happy to say that she remains well in herself and there are no signs of decompensation currently. She told me that her application for the additional payment for the Skipton Fund has been refused. I am not sure as to the exact reason, but it appears that though her AST, ALT, and ARPI index do not match the current Skipton Fund specification. However, she is already biopsy proven to show early micro-nodular cirrhosis from 1995. I have advised her to discuss this further with the Skipton Fund.*
>
> *Bloods done in clinic show normal renal function, except a mildly raised potassium of 5.1 LFT's shows a bilirubin of 8, Alk phos 68, ALT of 81, and Gamma GT 11. Alpha feta protein in progress. Her haemoglobulin was 14.1 platelet count reduced at 79 and PT 12.*
>
> *I have arranged for an ultrasound HCC screening and will review her back in clinic in October."*

102. This is also exhibited in a letter, dated 09 June 2008, from Professor M Bassendine, (exhibited as **WITN5606008**). The letter outlines the following:

> "***Diagnosis***: *Post transfusion hepatitis C (genotype 1a)*
> *Previous responder/relapser to combination antiviral therapy 1997-98*
> *Autoimmune hypothyroidism on replacement*
>
> *This is just a note to update you regarding the second part of the Skipton Fund application. None of the "indirect" indices are consistent with progression to cirrhosis. Your fibroscan liver stiffness value actually suggests relatively little fibroscan (4.4 kpa). Your AST to ALT ratio is less*

> *than 1 (0.709) and your APRI score is 1.525. In order to qualify for the second part you need an AST to ALT ratio greater than 1 and an APRI of greater than two and/or fibroscan in the cirrhotic range. It may be that the initial liver biopsy was misinterpreted and I will ask for further clarification on this. I can discuss this with you when you attend for review in July."*

103. I have no recollection of this having been discussed with me. She had previously actively encouraged me to apply, telling me that I was entitled to the Stage 2 Skipton Fund payment.

104. In 2018, I was informed that payments due to me will now come from the Scottish Infected Blood Support Scheme ("SIBSS"). As my horse-riding accident took place in Scotland, I am able to qualify for payment under the Scottish Scheme.

105. In 2018, I began to receive a payment of £1000 a year from SIBSS, of which, I had to fill in a form to outline the impact that HCV has had on my life. In retrospect, having dictated this statement, I now realise how much I have been in my denial and how much I played down the impact HCV has had on our lives, because of my attitude towards it. Mainly because of the way my **GRO-B** and I coped to make things easier for each other. This is now more prevalent after drafting my witness statement to the Infected Blood Inquiry which has highlighted that I, and also my husband, had actually been impacted much more than I realised and admitted to. I hadn't allowed myself to dwell on anything to do with the whole business and was deliberately in denial.

106. In July 2021, a payment appeared on my bank statement with the reference 'Nss.' There was no accompanying letter preceding the payment, and I was at a loss to know as to where the money had come. I now know that the acronym 'Nss' stands for the National Services Scotland and the payments are from SIBSS. Because I had my accident in Scotland. I have now learnt that that money was to catch up with payments others have received in other parts of the UK. On 21 February 2022, I received a letter telling me that my current

annual amount as from April 2022, will go up. I will also now get a monthly payment and each October a winter fuel amount. I am mystified because I have had no hand in my acquiring these sums. On enquiring I have been assured that the figures are right and that it is my entitlement.

Section 8. Other issues

107. In 1991, I had been told by a medical professional that they knew that the blood I was given had hepatitis, Not A or B but it had a hepatitis. If the medical profession knew that the blood was contaminated so far back but carried on using it, that is wrong. They should not have given a drop to anyone other than me because of the emergency. In effect, I suspect they were using the blood experimentally to see who got what In giving this statement I have realised the significance of the need to get blood for me urgently. I am so grateful, so any criticism I have made about my personally receiving contaminated blood is no longer said in anger for me but still for those patients who received the blood under normal circumstance.

108. My view then as outlined within a letter I had written to the Infected Blood Inquiry on 13 May 018, in response to a letter dated July 2017, (exhibited as **WITN5606004**), it outlines my belief surrounding knowledge of infection:

> *"I ask the question that if a test was available in 1978 to identify non-A non-B (and maybe before that) which indicated contaminated blood, why was such blood continued to be transfused and it declared that there was no test available before that, identifying the new hepatitis labelled Hep C in 1991. After 1978 I went regularly to ERH for check ups and to have blood taken. I was told that my blood was sent around the world and that not only was a third type of hepatitis being discovered but maybe more, the last I heard it was up to Hepatitis G, which I am led to believe is also a problem one."*

109. In 2011, I was contacted by letter from Professor M Bassendine, as to whether I wanted to participate in the HCV Research UK Hepatitis C Cohort Study, a long-term study into patients who have HCV. This was a study concerning the identification of reasons why patients are able to clear infection spontaneously, whilst in others the infection becomes chronic.

110. On 23 October 2011, I agreed to partake in the study, and I had signed a consent form which I recently discovered within my medical notes, but I have no recollection of what my involvement was. I didn't think anything further happened with it.

111. I wish to provide a witness statement to the Infected Blood Inquiry, as I want to help others who have found themselves in a similar position to myself. I think it is wonderful that the Inquiry has been set up. This was the first time I had told my story in full and have not spoken in such detail about it to anyone before. I feel that it would help other people to know that they are not alone in their experience.

112. I am very grateful for the National Health Service as they have given me forty-three years of life that I would not have otherwise had if it had not been for the blood transfusion, I received in 1978. If I had not received the blood as treatment, I would probably have died, which I already had, before any treatment, on arrival to the hospital, but was resuscitated. I was also told when I was in recovery that I would not have survived the accident had I not been so healthy. I found my soulmate two years before my accident in 1978, and I am so very grateful that the skills of the surgeons gave us so many more wonderful years together.

Statement of Truth

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

Signed GRO-B

Dated 06 June, 2022

Table of Exhibits:

Date	**Notes/ Description**	**Exhibit number**
12 January 1979	Medical Report, from the Royal Infirmary of Edinburgh.	**WITN5606002**
06 March 1979	Letter, from Dr N D C Finlayson, Gastrointestinal and Liver Service, Royal Infirmary of Edinburgh, to Dr Jenkins,	**WITN5606003**
13 May 2018	Letter, from Mrs GRO-B to the Infected Blood Inquiry.	**WITN5606004**
14 December 2015	Letter, from Dr John Jacob, Gastroenterology and Dr Stuart McPherson, Consultant Hepatologist, The Freeman Hospital, to Dr GRO-B	**WITN5606005**
26 April 2007	Letter, from Professor M Bassendine, Consultant Hepatologist and Professor of Hepatology, The Freeman Hospital, to Dr GRO-B GRO-B	**WITN5606006**
28 May 2010	Letter, from Dr Debaish Das, Specialist	**WITN5606007**

	Registrar in Gastroenterology/Liver on behalf of Professor M Bassendine, Consultant Hepatologist and Professor of Hepatology, The Freeman Hospital, to Dr GRO-B GRO-B	
09 June 2008	Letter, from Professor M Bassendine, Consultant Hepatologist and Professor of Hepatology, The Freeman Hospital, to Mrs GRO-B GRO-B	**WITN5606008**