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Witness Name: GRO-B

Statement No.: WITN4318001

Exhibits: WITN4318002 - 003

Dated:

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 11 August 2020.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1957 and my address is known to the Inquiry. I am a self-employed plumber and heating engineer. I live with my partner GRO-B who attended this interview to assist me with my statement. I also have a son aged 33.
2. I intend to speak about my infection with hepatitis C. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on me, my family and our lives together.

Section 2. How Infected

3. From age 7 to 13 I attended GRO-B initially in GRO-B and then in GRO-B Devon. I was admitted through a local authority after my mum died when I was 7, and also because I was a slow learner. I am now on the NHS waiting list to be tested for Dyslexia/Autism.
4. At the boarding school there was a medical room where we had regular check-ups. I remember receiving injections here also. The school also used an outside dentist who came to the school in a large van where all the treatments were carried out. I had numerous teeth removed and a brace fitted by this dentist. This has given me a huge fear of dentists.
5. In my late teens, I believe around 1979, I was involved in a road traffic accident. I remember this time well as it was before my father died, when I was aged 21, and was around the time I went from being employed to self-employed.
6. I was driving a motorcycle down a small country road. At a blind corner, my right leg clipped the wing of an oncoming car. The accident did not result in any police involvement, nor did I require an ambulance. It was 50/50 as to who was to blame. If this had happened in this era I would have called an ambulance using my mobile phone.
7. After the accident, I ended up with a lot of pain in my right knee, which was severely swollen. Through my GP, I was sent to GRO-B Hospital, GRO-B for an operation. I do not know what the actual operation entailed. I recall that I was anaesthetised throughout.
8. Following the operation, I had an aluminium slab down the back of my knee that covered the whole of the back of my leg, from the ankle to my waist. This was fitted for three months, during which I could not bend my knee at all. I had cartilage removed from the outer of my knee, with an

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investigation hole made on the inside. I had 12 stitches as they cut through my muscles as part of the operation. I do not know if I received a blood transfusion during the operation.

9. Some years later, in the mid to late 1990s, I began to experience difficulties with my health. I had severe pain in my back and right-hand side. I was also continuously tired, I felt like I could fall asleep on a washing line. I saw my GP, Dr Adrian Canale-Parola at GRO-B Practice, regularly over this 2 to 3 year period.
10. Eventually Dr Canale-Parola sent me for a blood test. When I returned to see him in the practice consulting room, I said that I had come for the results of my blood test. He laughed at me and said 'how many pints of Boddingtons are you drinking then?'. He told me that my liver function was around 480, and the normal score was around 50. He then said that he was surprised that other organs in my body hadn't packed up because of how high my LFTs were. Dr Canale-Parola said nothing else except that I should have another blood test in 3 months.
11. This incident angered me enormously. At that time, if I had even half a pint of beer I would be in bed for 3 days afterwards. I have never been a big drinker at all. If I ever went out with colleagues after work I would not be able to go to work the next day.
12. For 2 years after this first blood test, I was completely teetotal. Over this time, my LFTs dropped from 480 to 450, which was still very high. I continued to suffer from pain in my right-hand side. I did notice that this pain stopped temporarily after I went to the toilet. My GP thought that this may be related to my bowels. I was then referred to a gastroenterologist at Walsgrave Hospital, Coventry.
13. The gastroenterologist at Walsgrave Hospital (I don't recall his name) took blood tests and stool tests from me. He even insinuated at one stage that I was an intravenous drug user.

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14. After taking these tests, I returned a week or so later, around July 2003. With no warning, the consultant told me straight away that I had hepatitis C. He did not give me any information whatsoever, not even a leaflet. When I asked him about hepatitis C, he told me to go away and research it on the internet. At this time, in 2003, I was useless on the internet, and my dyslexia made this even worse. When I phoned GRO-B to tell her about my diagnosis, she was completely shocked.
15. Prior to beginning treatment for my hepatitis C infection, I had to undergo a liver biopsy. This was performed at Walsgrave Hospital, where I was a day patient. The day before, my bloods were tested to make sure that they clotted and to ensure that they had enough blood in reserve. I was told that I could die by bleeding to death during the liver biopsy. This was a massive worry and caused me a lot of stress.
16. I was in the hospital for around 6 hours after the operation so they could monitor me and ensure there was no internal bleeding. I wasn't allowed to drive for a week afterwards, which again meant that I could not work.
17. When I went back to the hospital for my results, I was told that I had severe to moderate scarring of the liver as a result of the hepatitis C. I did not have cirrhosis of the liver. They then said that they would 'let me have Christmas' and that I would start the treatment in January.
18. The day before my appointment, in early January 2004, I got a phone call from the hospital. They asked me to go to the pharmacy at the hospital and collect a prescription prior to my appointment. I picked up two carrier bags full of medicine, not knowing what was in them.
19. When I got to the appointment, I saw a hepatitis C nurse called GRO-D who had just started working there. He showed me the procedure for taking the treatment. There was a glass vial with a liquid in, and another small bottle along with one syringe and two needles, one big and one small. I was shown how to break the glass vial open with the bigger needle and how to draw the liquid out. This was then extracted into the

smaller bottle, with [GRO-D] showing me the correct measurements. He then injected it into the soft tissue in my stomach. I was also given a sharps bin, which was bright yellow and large. [GRO-B] found this quite offensive, even though she understood the necessity of it.

20. The treatment was a combination of interferon and ribavirin. The interferon was injected once weekly, as described above, and I took a ribavirin tablet twice daily. I was not warned as to any potential side-effects of the treatment, and in hindsight I was not given much help.
21. The medication I collected from the hospital pharmacy was to last me for two months. Once injected, the side-effects from the interferon would take 3 to 4 hours to take effect. The best way to describe the side-effects is like I was receiving a really bad dose of the flu.
22. On the first Friday after starting the treatment, when injecting myself for the first time, I cut all my fingers open when trying to open the glass vial. This happened on two or three further occasions. I had a lot of difficulty transferring the liquid from one bottle to the other. I also had bruising all over my body from where I injected the interferon. My partner was unable to help me as she is afraid of needles.
23. The side-effects from the interferon were horrendous. I lost all sense of taste and had blisters and ulcers in my mouth and on my lips. I also suffered from hair loss, and had virtually lost all of my hair by the end of the 6 month course of treatment. I also lost my libido, which has not returned even to this day. When I spoke to my GP about this, he said that I was just lucky to still have a partner.
24. I returned for my second appointment at Walsgrave Hospital two months later. After seeing [GRO-D] the nurse, I asked 'do I just collect my prescription on the way home?' as I had run out of medication. He said that they didn't keep that in stock and they would have to order it in. When I returned to the hospital pharmacy 2 or 3 days later, I was told that I had to pay for the medication. I explained that the first batch of

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medication was free and that I did not have any money. They said that I was lucky to get the first batch free and that I had 'got away with it'.

25. On the third occasion I saw the hepatitis C nurse at Walsgrave Hospital, a further two months later, I had to ask again for my medication. They said they would order it in, but I refused to come back all the way to Coventry. They then arranged for it to be delivered to **GRO-B** Hospital, **GRO-B** where I collected it.

26. After six months of the interferon and ribavirin treatment, I returned to the gastroenterologist. I had blood tests for the first time since starting the treatment. He said that I should have phoned them beforehand. I explained to him that I was experiencing severe mental issues during the treatment. This ranged from shouting at the TV and at passing cars to verbally abusing my partner **GRO-B** and my son. I did not understand any of this, and it was completely out of character.

27. Towards the end of my treatment I said to my GP that I needed anger management therapy. I explained that I was shouting at cars on the road nearby and had uncontrollable rages directed at my family. I would have a day and a half of normality before having another interferon injection and it would start all over again.

28. I was also extremely fatigued throughout this course of treatment. I became weak physically, and was forced to sleep on the sofa as I could not get up the stairs. I went from being 14 stone at the start of the treatment to 11 stone at its completion, nearly all caused by muscle loss. I was previously very active, going swimming regularly and also working kept me fit and strong. I went from this to sleeping for 10-12 hours a day or more.

29. At this time, I had my own plumbing and heating engineer business. Even before I began treatment, my fatigue meant that my business began to be affected. I went from employing 10 people to employing

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none. I was completely unable to work because of the fatigue prior to my diagnosis, and during the subsequent treatments.

30. **GRO-D** the hepatitis C nurse at Walsgrave Hospital, put me in touch with a local support group. When I phoned them up, I was quick to work out that most of the people were intravenous drug users. The person who answered offered to meet me in a pub car park. I went to the arranged meeting place and sat there for an hour before leaving. The next day he phoned me back to apologise but I told him to forget it. After that I stopped pursuing the local support group. I do not believe that this group was an NHS-funded or NHS-affiliated body, though I believe it was connected to Walsgrave Hospital in some way.
31. After this experience, I used my own initiative and found a support group based at **GRO-B** Hospital. I had a daily 1-to-1 phone call with a person called **GRO-A**. **GRO-A** had experience of people with hepatitis C, and I believe she set the support group up. She helped me enormously to the point where I trusted her with all my problems.
32. In particular, **GRO-A** told me about a booklet called 'Taking Control'. She explained to me that the treatment gives you short term memory loss and there are lots of side-effects. 'Taking Control' was a log that I could have used to write down what I had done that day. If I was given this at the beginning of my treatment, it would have been a massive help.
33. **GRO-A** was amazed that I had not been given anything by the hospital with regard to my hepatitis C infection. She told me that I needed to go on antidepressants, and she sent me lots of useful leaflets containing information about the virus. I went to see my GP and I was prescribed antidepressants. However I decided that I did not want to take any more tablets as I was bad enough with all the other medication. I did not bother taking them in the end.
34. My depressive episodes are recorded in my medical notes, which I have given to the investigators and attach as **exhibit WITN4318002**. On

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reflection, I believe my anger derived from my depression. Being on my own did not help as GRO-B was at all work all day whereas I was at home all alone. GRO-B has since told me that she was frightened to come home as she was afraid of how I would react.

35. GRO-B says that I would often be ranting at the TV, and my behaviour was that of a different person. At that stage we had been together for around 10 years, and GRO-B knew who I really was. By then, I was completely unpredictable.

36. I went back to Walsgrave Hospital to see the gastroenterologist when I had completed the six month course of interferon and ribavirin treatment. He said to me that they had done the tests, that the treatment had not worked and that I was still infected with hepatitis C. This was completely devastating. It made me remember how I felt when I was first diagnosed. That day, I went straight home and had a shower, scrubbing myself red raw. I felt dirty and thought that the infection was my fault.

37. When I was told the treatment had not worked, I went back to Walsgrave Hospital with all the leaflets that had been given to me by GRO-A and the support group. The consultant said that they had all of these leaflets on the shelf. I replied saying 'well why didn't I get given them?'. He refused to take them off me.

38. The consultant said that I was entitled to one lot of treatment and one lot only. Although they had told me at the start that there was a risk it would not work, I now felt hopeless. I asked him 'where do I go from here?'

39. I was referred to Nuffield House, Queen Elizabeth Hospital in Birmingham, following a meeting with my GP. There I saw a Dr Hayden. The atmosphere at the Queen Elizabeth Hospital was completely different to Walsgrave Hospital. The staff were welcoming and understanding of my situation.

40. Dr Hayden had taken my blood tests and viral load tests, and said that he needed my records from Walsgrave Hospital to re-examine my liver

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biopsy. This was to ensure that we were going in the right direction. When he contacted Walsgrave Hospital, they said that they had lost my liver biopsy notes and results. Dr Hayden said that he could not get any of my records from Walsgrave Hospital.

41. Dr Hayden did not want to put me through another liver biopsy. He explained to me that I had been prescribed the wrong dosage of interferon, and wanted to re-treat me on this basis. He said that I was given 20% below what I should have been given.
42. Dr Hayden said that there were two companies who made the interferon medication, one of whom provided the drug in a preloaded syringe so I did not have to mess around with the glass vials. The only problem, he said, was that they needed paying for the treatment because I was outside of their trust area. As such, my Primary Care Trust had to pay for the course of treatment. Dr Hayden said that he would write to **GRO-B** Primary Care Trust and advised me to continue pushing them to pay for my treatment.
43. **GRO-B** researched **GRO-B** primary care trust and found that Dr Canale-Parola, my GP, was on the board of trustees. In light of this, we went to see him to discuss my next treatment, though did not let on that we knew he was on the board. Dr Canale-Parola told me that I should write to the Primary Care Trust, even though he knew I am severely dyslexic. When I asked for the telephone number of the trust, he wrote it down from the top of his head straight away.
44. When I phoned **GRO-B** primary care trust they said that I could only have one course of treatment. Because of this, I would have to go away and live with the virus. I had a list in front of me where I had recorded all of my complaints made against Walsgrave Hospital for the way they had treated me. I read these out to the person on the phone and said that I would drop all 16 complaints if they allowed me to have the treatment under the care of Dr Hayden at Queen Elizabeth Hospital, Birmingham.

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45. **GRO-B** Primary Care Trust phoned me back within an hour and said that would pay for my treatment at Queen Elizabeth Hospital, Birmingham, on the grounds that I did not receive a full course of treatment during my first course, as my dosage was lower than it should have been. I believe the cost was around £500-600 a week for the interferon.
46. The second course of interferon treatment began 6 months after I finished the first treatment, around January 2005. Dr Hayden recommended that I start a course of antidepressants before starting the interferon treatment as it would help me to cope with the side-effects. He also said that I would be checked much more regularly throughout the course of treatment, as this was not done whilst under the care of Walsgrave Hospital.
47. The interferon injections were administered to me by a nurse once a week. I also attended Queen Elizabeth Hospital, Birmingham, every week for the first 10 weeks of my treatment for monitoring. I had a viral load test after four weeks. During the first treatment, Walsgrave Hospital said to me that they wouldn't do a viral load test because it was too expensive.
48. The side-effects of the second treatment were much less severe. I felt a whole lot better during this course of treatment. The treatment lasted for 12 months, which I believe ended in 2007. Upon completing the course of treatment my viral load tests showed that I had cleared the virus. I have had viral load tests since completing the treatment that have all shown that I am clear of the hepatitis C infection.
49. In January 2020 I felt ill so I had a viral load test, and this again showed normal results. As far as I am aware I have no cirrhosis of the liver.

Section 3. Other Infections

50. I do not believe that I have, or have had, any other infections apart from hepatitis C as a result of receiving an infected blood transfusion.

Section 4. Consent

51. When I visited the gastroenterologist at Walsgrave Hospital, I was not informed what exactly I was being tested for. I did consent to all these tests as I wanted to establish the cause of my constant fatigue and pains.

52. Once I was diagnosed with hepatitis C, I consented to all testing and treatment with regard to my infection.

53. I was given very little information about my infection and the risks to myself and other people. I was not told anything about intimacy and passing it onto my partner. I was told that any spilt blood should be cleaned up with neat bleach and I had to notify the hospital or dentist if I had an upcoming appointment. Aside from this, I had to do a lot of my own research, and I was helped by GRO-A at the support group.

Section 5. Impact

54. My infection with hepatitis C, and my subsequent treatment with interferon, has had a dramatic impact on me. Before my diagnosis I ran a successful plumbing and heating company, employing 10 people. By the time I was diagnosed and receiving treatment, I had to let all of these 10 employees go.

55. As I was so tired and fatigued, my work gradually dried up. I would get enquiries from customers but I could not meet their demands owing to my illness. To this day I have not got these customers back. I managed to start working again after clearing the virus. However, 3 months later I

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had a heart attack, on 16 December 2007. I then chose to fold my business and took a job as a plumber for the local authority on PAYE in November 2015. This lasted until February 2019 when I chose to resign after false allegations were made against me by my manager.

56. I have tried to continue as a self-employed plumber, but this has been challenging. I had to update all my training and qualifications. I am still trying to build relationships with a new client base.

57. I did not have insurance for sickness as I was self-employed at the time of becoming ill. As a result, I was unable to claim for loss of earnings. I was forced to claim incapacity benefit, which was extremely difficult to access. I had to get sick notes from my GP as evidence, and I received incapacity benefit of £58 a week. The payments were not regular and I had to depend on GRO-B for more financial help, adding more strain to our relationship.

58. This payment was suddenly stopped, and I had to attend a medical assessment to continue claiming the benefit. I was told to go to Coventry for a meeting at the health and pensions department. At the building I struggled to get up the stairs because I was so weak. During the interview, I asked to go to the toilet. When I came back, I got completely lost. I was disoriented and confused.

59. The medical assessment team told me that I was fit to work and that I did not score enough points to stay on the incapacity benefit. GRO-A, from the support group, then gave me some benefit forms to complete. She told me exactly how to complete the forms and how to word my answers. I was then granted long-term sick benefits that did not require regular sick notes from my doctor.

60. I remember seeing a female doctor called Dr GRO-D who said to me that 'you want the magic tablet that makes it all go away'. I sarcastically replied 'yes please' and never saw her again.

61. As already described, the side-effects of the first course of interferon and ribavirin treatment were horrendous. I had teeth removed, pain in my gums and countless cold sores and ulcers in my mouth and lips. Whenever a cold or flu was going around I would get it due to my weakened immune system. I also lost control of my bowels, which continues to this day. The fatigue was completely draining, and I also had regular fits of rage and unexplained losses of control.

62. I have problems with high cholesterol. I have tried virtually every type of statin treatment available to treat this, but I am unable to tolerate the statin tablets. I suffer from terrible side-effects. I believe it is because my liver is severely to moderately scarred, meaning I cannot cope with the effects of the statins. I was invited to participate in a clinical trial conducted by Oxford University to lower my cholesterol levels. This was meant to involve an injection every 6 months, but at the appointment they refused to treat me because of my previous hepatitis C infection.

63. Soon after my diagnosis with HCV, GRO- was worried that she could have contracted the virus from me. None of the doctors either advised or arranged for GRO-B to get tested. She had to get tested at a drug clinic, which was a degrading experience. Thankfully, she tested negative for HCV.

64. GRO-B really struggled to deal with my mood swings and uncharacteristic behaviour. She later told me that she was scared to come home from work as she didn't know what sort of mood I would be in. I was reliant on GRO-B for taking me to hospital appointments which affected her work.

65. During this 3 year period I only ever had one visitor. My 'friends' rarely visited me, and I shut myself away due to the embarrassment of my diagnosis. I knew that the virus was associated with homosexuals and drug users. I ended up being a loner, and only a handful of people knew about my infection.

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66. When I was working as a plumber for the local authority, I told a few colleagues about my previous infection with hepatitis C. Almost overnight they began to ignore me. This was despite the fact that I did not even have hepatitis C at the time. I believe they spoke behind my backs, and this only goes to show the stigma associated with the virus even now.
67. Whenever I went for dental treatment, I was always the last patient of the day so they could clean the equipment afterwards. This was the same when I was stented for my heart attack, when I was the last person in the theatre that day even though I had tested negative for hepatitis C at the time.
68. I was a blood donor from 1981 up to around 1985, roughly 15 years before my diagnosis with HCV. I enclose my blood donor booklet, showing donations given during this period, as exhibit **WITN4318006**.
69. My son, knowing that I was coming to this interview, sent me the following text message: "Losing out on time with my Dad during a crucial time in my life (developmental years) that we can't get back. Stress and anxiety for me that I didn't really understand. Fear."

Section 6. Treatment/Care/Support

70. I had a lot of difficulty accessing treatment for my hepatitis C infection. In the first instance, I was given vials of interferon that were difficult for me to administer. I cut my hands on multiple occasions trying to extract the liquid from the vial, eventually I was told I should have been using a towel in my hands to protect them which was all well and good in hindsight.
71. Having completed the treatment, and endured all the horrendous side-effects, I was then told that it had not worked. On top of this, I later find out that I had not received the correct dosage. Dr Hayden told me that I received 20% less than I should have done.

72. I then had to fight to get my second interferon treatment paid for. Dr Hayden was helpful in lobbying the **GRO-B** Primary Care Trust to pay for my treatment at Queen Elizabeth Hospital in Birmingham. However they initially rejected my requests for support because I had already received one course of treatment.

73. I received no support from my GP, Dr Adrian Canale-Parola, despite him being on the board of trustees. Ultimately I was forced to use my list of complaints against Walsgrave Hospital as bargaining chips for them to fund my treatment at Queen Elizabeth Hospital.

74. The treatment and support I received from Dr Hayden at Queen Elizabeth Hospital, Birmingham, was exceptional. In comparison to Walsgrave Hospital, it was a completely different atmosphere. I felt respected and welcomed, and supported throughout all my second course of treatment. My partner **GRO-B** also felt much more comfortable and welcome at Queen Elizabeth Hospital.

75. In hindsight, I believe that I should have been diagnosed with hepatitis C much sooner. I saw my GP regularly over a period of 3 or 4 years with constant fatigue and back pains. I believe I should have been tested much sooner, and this could have alleviated a lot of the suffering.

76. I had to find a psychological support service myself. I was initially recommended to a support group for intravenous drug users, and they treated me unprofessionally by offering to meet me in a pub car park. **GRO-A** from the support group affiliated to the Royal Devon and Exeter Hospital was of immense help to me. I found her group from my own research, and I was not offered any other form of counselling or psychological support.

77. When I asked my GP for anger management therapy during my first course of treatment, I was told that I should go on antidepressants. I

initially refused to do so as I did not want to take any more tablets. I eventually started antidepressants on the advice of Dr Hayden prior to starting my second course of interferon treatment.

Section 7. Financial Assistance

78. Sandy, from the support group, told me about the Skipton Fund around 2009. I received the application form and filled in what we could. Some sections had to be filled in by my GP, Dr Canale-Parola. I went to **GRO-B** **GRO-B** Practice and had to pay my GP £115 to fill the form in, before I sent it off to the Skipton Fund.

79. I received the form back from the Skipton Fund several months later as the form had not been filled in correctly by my GP. It was not signed and dated, and he had not even completed the necessary sections on the form. I returned to my GP practice to have it completed correctly. Dr Canale-Parola did not look at my medical records. He simply wrote that it was his opinion that I had not received any blood products.

80. I do not believe that my GP looked at my records, and therefore has no right to comment, as the form was completed in a rush on the day. I have absolutely no respect for my GP Dr Canale-Parola for this and for the way he has treated me.

81. I received a reply from the Skipton Fund in November 2009. The Skipton Fund rejected my application because of a lack of evidence that I had a blood transfusion in 1979 after my road traffic accident and subsequent operation. They suggested that I could go back to the hospital to get my records. After all the issues I had, I could not be bothered with all the stress of the application process.

82. Walsgrave Hospital had lost my liver biopsy results and other records requested by Dr Hayden, so I did not see a lot of point. I even remember visiting the hospital when it was being rebuilt and recall seeing boxes of

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files and papers everywhere all over the corridors. We gave up with the Skipton Fund application process after receiving this letter.

Section 8. Other Issues

83. I feel grossly let down by the NHS, especially Dr Canale-Parola and Walsgrave Hospital with the way I was treated and the lack of information given to me about my infection with hepatitis C. This has left me with a total lack of confidence in the NHS due to the non-existing care and following up from my first lot of treatment.

84. I feel that a great part of my life has been affected by this. I've been mentally scarred, my business has been virtually non-existent, my relationship with my son has been permanently damaged and there has been a great strain on my relationship with GRO-B

Statement of Truth

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

Signed GRO-B

Dated 21-10-2020