Witness Name: GRO-B
Statement No.: WITN0452001
Exhibits: **WITN0452002 – WITN0452006**
Dated: 19.3.2019

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 14 March 2019.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1945 and my address is known to the Inquiry. I am retired and live with my partner GRO-B

2. I intend to speak about my infection with the Hepatitis C Virus ("HCV"), which I contracted as a result of receiving an infected blood transfusion.

3. In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment I received, and the impact it had on my life and the rest of my family.

4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

Section 2. How Infected

5. In September 1975 I haemorrhaged. I suffered extensive menstrual bleeding throughout the day but made it to bed. I got up in the night and passed out. My daughter found me lying on the landing. I was rushed to King's Mill Hospital, Mansfield, in an ambulance and was given a blood transfusion.

6. I was conscious whilst receiving the blood transfusion. I saw a blood bag on a stand, with a tube coming out of it and going into a cannula, which went into a vein in my arm. I knew it was clearly blood because it was red.

7. They used three bags, one after the other. I was transfused with three pints of blood. That was the only blood transfusion I have ever received.

8. I was never warned of any risks of infection from the transfusion. I was just rushed into hospital, and transfused straightaway.

9. I was infected with HCV from being given contaminated blood in the transfusion.

10. As far as I am aware, there were no obvious direct symptoms of the HCV. I had suffered from arthritis, but I cannot say this was due to the HCV. Time passed and I did not find out I had it until many years later.

11. I went in to my local doctor's surgery, GRO-B for a routine blood test in March 2006. I was getting older, we had private healthcare, and I just wanted to check. They were testing for anaemia, testing my blood sugar levels and so on.

12. One of the results came back not right. It showed damage to my liver. My doctor, Dr Richard Hook, thought it was cirrhosis. He questioned me about drinking and drugs. I told him I'd never touched drugs and rarely drank, and if I did, it would be one pint of bitter for a special occasion.

13. I have never had tattoos, never had promiscuous sex and have only had my ears pierced, when I was 26 years old, I have no piercings.

14. It was obvious; he thought I was lying. He asked me if I was sure, and how many units a week did I drink. It was awful. He never once asked about transfusions or HCV.

15. Dr Hook arranged a second blood test pretty much straightaway. He told me "it's not good news" and that I had HCV.

16. He said it can be life-threatening and explained the only treatment was with Interferon and Ribavirin. He told me the side-effects of these drugs were terrible. I remember him telling me this face-to-face. He told me "it could be worse, I could be telling you that you have cancer".

17. He said it was usually drug addicts and gay people who had it. I thought 'there is no way I can have that!'.

18. He didn't explain any more than that; I don't think he knew very much about it.

19. I do not recall ever being given an information leaflet on HCV.

20. He referred me to Dr GRO-B at GRO-B straightaway. I don't think this could have been done sooner. I had private healthcare and so saw Dr GRO-B almost immediately. He asked me questions, and in particular I remember him asking, if I had ever had a blood transfusion.

21. Dr GRO-B looked at my blood test results and confirmed that I was infected with Genotype-1a HCV. He obtained evidence from my GP that I had undergone a blood transfusion. I exhibit a letter, dated 9 March 2006, showing when I was informed that I was infected **[WITN0452002]**.

22. He carried out a liver biopsy on me, on 27 March 2006, in GRO-B GRO-B I exhibit a discharge note showing this **[WITN0452003]**. Dr GRO-B was a lot more understanding than Dr Hook. He put me at ease and was just amazing. He explained that the biopsy showed scarring of the liver, but that it was minimal.

23. He told me about a drug trial that had just started. This was to be taken alongside Interferon and Ribavirin. He said that considering I had Genotype-1a HCV and had a high viral load it would be better to wait before undergoing the treatments, because the chances of success were slim and the side effects were terrible.

24. I had regular blood tests and was monitored extensively for a number of years. I exhibit a letter from Dr GRO-B dated 27 May 2010, confirming that I would wait for a promising clinical trial before attempting treatment **[WITN0452004]**.

25. Dr GRO-B told me it could only be transmitted from blood-to-blood contact. This reassured me as, I had been terrified of passing it on to my grandchildren by kissing them or holding them. However, I would go into a panic if I cut my finger doing the veg! I would have to rinse it, put kitchen roll on it and put on plasters immediately. It made me paranoid.

26. My own common sense told me to be careful with toothbrushes and things as gums can bleed.

27. I don't think Dr GRO-B could have told me sooner, or given any further information.

Section 3. Other Infections

28. I do not believe that as a result of being given infected blood I have contracted any infection other than HCV.

29. Dr GRO-B did additional tests as soon as I saw him. He said he had to test for AIDS and Hepatitis B. It felt awful being told that. I have been tested many times for other infections and I only had the HCV. I feel lucky; it could have been even worse.

Section 4. Consent

30. I have been asked whether I have ever been treated or tested without my knowledge or consent. To the best of my knowledge I do not believe I have.

31. The treatment I undertook for my HCV infection was part of a drug trial. This was done for research and I was never informed what drug I was taking alongside the Interferon and Ribavirin. However, I consented to this treatment at all times, and would have signed documents to that effect.

Section 5. Impact

32. After the transfusion, I wasn't really aware of any physical effects. I had a hysterectomy around three years after the transfusion, which really knocked me down, but I didn't attribute that to HCV.

33. My memory is hopeless these days! I call my sons by my grandsons' names, and I am terrible with dates. However I cannot say that is due to the HCV; I could just be getting older!

34. I think the effects of HCV were more mental. After I found out I had it, every time I felt down or unwell I assumed the HCV was responsible. It is always in the back of your mind. I couldn't sleep after I found out about it. I worried terribly. I worried when I had a throat or sinus infection that it was as a result of the HCV.

35. I was terrified of passing it on to my family. I was so worried I may have given it to my grandchildren. My great-grandchildren were born after I found out I had HCV. I was scared to kiss them. I'd love to have asked my grandchildren to have the HCV test, but I daren't because I knew they would talk to people.

36. I have suffered subsequent medical conditions as a result of my HCV infection. My liver has suffered from fibrosis, which has been confirmed by two liver biopsies.

37. Biopsies are very uncomfortable; you can't eat or drink before, you can't sleep, and you have to stay very still for several hours. It can also be very painful. You can feel the needle going in. When it goes into your liver, you feel a 'pop' and that's when you know it's actually gone in.

38. I have also suffered from cramps in my feet, my legs and my midriff. I have seen other people with HCV complain of similar symptoms in The Hepatitis C Trust newsletters, but who is to say it is due to the HCV?

39. I was initially randomised and entered into a Boehringer Ingelheim drug trial treatment for HCV on 3 January 2011. However, I was informed that because I was taking medication to treat high blood pressure, that I could not be entered into this trial. I had been taking that medication for almost thirty years and was upset at having been all worked up to begin the treatment, and was then let down.

40. Two years later, in April 2013, I began my 24-week treatment in another Boehringer Ingelheim clinical trial.

41. I would see a nurse once a month at Queen's Medical Hospital. She would provide me with a month's worth of tablets, capsules and injections. She showed me how to administer it, what to take, everything.

42. I took two Copegus (Ribavirin) tablets in the morning, and three in the evening with food each day. I took the trial drug capsules twice a day for the first twelve weeks, and then took one tablet a day for the second twelve weeks.

43. I was injected with Pegylated Interferon once a week on Fridays, in the late afternoon. GRO-B would do the injections for me. The first time I saw the nurse she tried to have me do them myself. She said 'Just stick it in! You've got to!' but I couldn't do the injections myself. I just couldn't.

44. This six-month drug trial treatment for HCV concluded in October 2013 and was successful in clearing me of the virus. I exhibit a letter, dated 24 October 2013, from Dr GRO-B showing this **[WITN0452005]**.

45. I do not feel there were any other treatments I could have received. I had only heard of Interferon/Ribavirin and the drug trials were just coming in.

46. The mental and physical effects of the treatments were severe. The night of my first injection in particular was horrendous. I had been warned by the nurse that it would be awful, this was the only reason I didn't go to A&E. I had been injected at Queen's Medical Hospital and felt absolutely awful. I went to bed as I felt so bad, but was shaking uncontrollably all night from head to toe. It was horrible! I was freezing, but also felt terribly hot. By morning the shaking stopped, but I was worried it would be like that every time. Luckily it didn't affect me as much after two or three injections.

47. The treatments also made me depressed. The last two months of the injections made me feel so down and I just didn't want to talk to anybody. I wanted to cry. I had never been like that before or since. It was really hard. I thought 'I don't think I can do this much longer'.

48. After four months of the trial I knew I would have to continue to the end of the treatment plan. I said that I was finding it really hard, but a nurse told me my tests were showing I had cleared the virus. I was crying out of relief when she told me that. That really kept me going. I don't think I would have been able to do the treatments any longer than I did.

49. After the trial finished I was told at Queen's Medical Hospital my thyroid levels hadn't returned to normal. I was told to give it time and it will come back on its own.

50. I felt so ill. It felt like my body was dying on the inside. My feet, legs, face and hands all swelled up. I didn't know what it was at the start, however I saw Dr Hook and he knew straightaway. He told me I had thyrotoxicosis. He was a bit mad! He said he didn't mind the trial drugs, but that he wished they had kept a closer eye on me, after it was over.

51. He told me he would ordinarily use a high dose of thyroxin to cure it, but that he couldn't, due to the effects of the treatment. He had to start on a low dose to sort it out. He started me on 25mg tablets, then 50 mg, then 100mg and then I think at the end, it was 175mg. That stabilised me. I still take thyroxin tablets now, 75mg a day, and will have to take them for the rest of my life.

52. Healthcare professionals have treated me differently as a result of my HCV. Before my treatment, I had to undergo surgery on my shoulders, to correct shoulder spurs. I saw a private consultant, Mr Manning, at GRO-B GRO-B

53. This consultant was lovely, but whilst I was in pre-op waiting for the operation, he came in and told me I had to be the last one in the theatre after the operation, because I had HCV and they would have to deep clean everything. I thought 'shouldn't it all be cleaned and sterilised anyway!?'.

54. He made it sound like was doing me a favour by doing the operation when I had HCV. It was horrendous. It devastated me, that I was treated in such a manner because I had HCV.

55. I have never seen my doctors' notes or records, and so I do not know if they show that I need to be treated differently because I had HCV.

56. I was paranoid about potentially passing the virus on through the dentists. However I have had no problems whatsoever. They always treated me right, even though I had told my dentist about my HCV.

57. I have always been worried about the impact it has had on my family. I never went on anti-depressants and that is where my family and GRO-B have helped me out so much. They have supported me through it all. We are a very close family and we do things together all the time, including walks, bike rides, holidays and days out.

58. I have just been so worried about possibly passing it on to my family. At one point I thought about only drinking from my own cup, even though I knew I couldn't spread it like that. I have only told GRO-B and my two daughters, as I am worried about other people knowing. GRO-B was tested as soon as we found out, and that came back negative. That was such a big relief.

59. I have been asked about the effects HCV has had on my social life. I do not believe there has been too much. The only thing is, that I have tried to keep it to myself as I come from a small village and word of mouth gets around so quickly. We never used to really go out much anyway.

60. I have found the stigma to be the worst thing about having HCV. It is terrible. People think they have only got to touch you to get it. I feel people should be educated, and taught that it can only be spread blood-to-blood. I didn't want people to know, so they wouldn't ask me about it. Not being able to tell people, to share your thoughts, is horrible. I felt I had a really dirty disease. People link HCV to drugs and fear that I'm contagious.

61. I have been asked about the educational, work-related and financial effects of being infected with HCV and going through the treatments. I do not feel there has been much, as I found out later in life I wasn't planning on studying and it didn't affect my work. I am lucky to have GRO-B who is still working.

62. The HCV was just an instant blast to mine and GRO-B's relationship. It definitely affected us. He wanted to try and carry on as normal, and helped make it as normal as he could. There was just nothing we could do about it for years. It seemed hopeless, but GRO-B was always there to support me.

Section 6. Treatment/Care/Support

63. I do not believe I have ever faced obstacles or difficulties in obtaining treatment as a result of my HCV.

64. However, I was recently provided with a HCV test that I could do at my local hospital. I was provided with an envelope from the Hepatitis C Centre at Queen's Medical Hospital. I took that in to GRO-B and got tested. I wanted to make sure I was still cleared of the virus. I completed the test and gave them the envelope. They were supposed to send it back to Dr GRO-B I never heard anything back. Two weeks later I called up and no one knew where it had gone. Both Queen's Medical Hospital and my doctor told me they never received it!

65. I think I always knew I could receive psychological support if I asked. Dr GRO-B may have offered me counselling when I was told I had the infection, but I cannot remember. At the Hepatitis centre there was a nurse called GRO-B I would often call during the treatments. She was lovely, always available to speak to, and I got to know her. She gave support to me throughout the medical trial.

Section 7. Financial Assistance

66. I first became aware that financial assistance was available on the day that Doctor GRO-B told me I had HCV, in 2006. My daughter was with me. It was a bit of a surprise! He told me I was entitled to a one-off 'goodwill gesture' of £20,000 from the Skipton Fund. He said it wasn't classed as compensation. I was gobsmacked when he told me that!

67. Either Doctor GRO-B or his secretary completed the forms and sent them off, after obtaining evidence from my local GP. I received the £20,000 from the Skipton Fund into my bank. It was only around six weeks after he sent off for it. I exhibit an invoice, which shows this was paid to me on 27 July 2006 **[WITN0452006]**.

68. I remember being told that if my liver deteriorated severely they would give me another £25,000. My liver never got that bad, and I was cleared of the infection after the trial, so I only received the one-off payment of £20,000.

69. I have been asked if there were any preconditions, or obstacles to receiving this payment. To the best of my knowledge there were none.

70. I currently receive £333 a month from the England Infected Blood Support Scheme ("EIBSS"). I have a basic pension, which is next to nothing, so the £333 a month is very helpful and nice. I also receive an annual winter payment allowance of £519. This is really most useful for me over the Christmas period. But at the end of the day I'd rather not have had to suffer and go through HCV.

71. I receive letters from EIBSS letting me know of possible benefits, and income top-up schemes. However, my partner GRO-B still works and is earning well. As these schemes are means-tested and calculated on household-income they don't really apply to me.

Section 8. Other Issues

72. I have been asked if I have ever been involved in any campaigning or litigation; I have not. I would really love to help people that have gone through what I have, but, I am afraid to put myself forward for something like that, because then people will know about me.

Statement of Truth

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

Signed GRO-B

Dated 19.3.19