ANONYMOUS

Witness Name: GRO-B
Statement No.: WITN0507001
Exhibits: **WITN0507002**
Dated: 8/8/2019

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 4th April 2019.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1950 and my address is known to the Inquiry. I am a personal assistant working in the NHS and I intend to speak about GRO-B: H my late husband, who contracted Hepatitis C infection from contaminated blood products. The impact of this infection exacerbated my husbands renal condition, affected his haemodialysis treatments and also his access to a surgical operation, which would have prolonged our lives together. My husband's medical number was GRO-B

Section 2. How Affected

2. H and I met in 1972, in our twenties, at a local dance hall. He was a barber and at one stage he owned and managed several successful barbershops. This was a happy time for us; we had a fun active normal married life as a couple. We would go abroad skiing three times a year and played badminton. We were happily married for 11 years before he suffered from renal failure that led to him receiving contaminated plasma from which he contracted Hepatitis C, which, in turn ultimately affected his access to life-saving surgery.

3. In around July 1985, I recall it was at the time of the Live aid concert, we had begun noticing that H s ankles were swollen and that he was tired all the time. H was not a smoker, but from childhood he always had to clear his throat. The doctors were originally baffled with these symptoms. Eventually, the Royal Hallamshire Hospital, identified that H had an untreated streptococcal throat infection, which was affecting his kidney function. It was only when they started looking into his symptoms of always having to clear his throat that they realised that it was connected to his kidneys; it was like a meningitis type virus that attacked the nephrons in his kidneys. He was then diagnosed with glomerular nephritis, which required steroid treatment.

4. H had three steroid treatments, via infusion, but after receiving one particular infusion he suffered from a horrific adverse reaction. On this occasion, he felt fine after his treatment but later on that evening I had to call 999, at midnight. H was having heart palpitations and was sweating a lot. I thought he was having a heart attack. We had to wait twenty minutes for the ambulance to arrive, that was the longest twenty minutes of my life. H was in such distress.

5. At Royal Hallamshire Hospital the doctors explained that his symptoms were due to an adverse reaction to the steroid treatment. They said

that the treatment affects people in different ways, but it is my belief that the treatment was infused too quickly on that occasion.

6. After that we were referred to the renal unit as the steroid treatment had failed. The doctors said that for 95% of people the steroid treatment worked, but unfortunately for H this was not the case.

7. In the Renal Unit we saw Consultant Nephrologist Dr Colin Brown, who recommended that H try plasma exchange. He was still filling up with fluid because his kidneys were not functioning properly. Plasma exchange is similar to a blood transfusion; they put H on to a machine which separated his plasma from his blood and then infused him with donated plasma.

8. The old plasma then comes out into a tube that drains into a big bottle on the floor and it looks like peach melba. The new plasma came in a big, 18 inch, bag of saline, and had a pale and cloudy appearance. I remember that it had Baxter written across the bags.

9. The renal nurse used to put it on the windowsill to warm it up for H because he used to get very cold during the treatment and sneezed constantly. He had this treatment once a fortnight for 18 months, between 1985-1987.

10. This treatment worked for a while and without it, his kidneys probably would have failed much sooner. When he first started plasma exchange his kidney function was 75% but then it gradually decreased to below 20%.

11. At that point, in 1987, his health was deteriorating and he had to go on to haemodialysis. I believe that my husband was infected with Hepatitis C from the plasma exchange treatment.

12. H did not have any tattoos or piercings and did not engage in promiscuous sex or drugs.

13. My husband and I were not advised of any risks of exposure to infection as a result of using contaminated blood products.

14. My husband and I found out that H had Hepatitis C during a routine three monthly follow up appointment, at the Northern General hospital in 1995. Here we saw Dr David Throssel, a Consultant Nephrologist where a set of routine blood tests were carried out on each visit. These blood tests included haemoglobin, potassium, whole blood count, liver function, urea and electrolytes levels.

15. On this occasion, the doctor said that he didn't need to see H again until the next scheduled appointment as everything was normal. He said that he will just get these bloods done. At that point, he was flicking through his notes to the blood forms that were at the back of H s file.

16. He then proceeded to stick a yellow 'category 3 risk' sticker on H s blood test forms. I asked him why he was doing that, to which he replied that he believed H was Hepatitis C positive.

17. He replied as if I already knew that H was infected, he flicked back through older blood tests. It seemed as if they had known that H was infected for some time. He obviously was tested for it at some point, but we were never consulted about this test nor told its outcome.

18. Also, had I not worked in the medical profession I would not have known the meaning of that sticker, which is just yellow in colour. They knew that I was a Medical Secretary and was familiar with medical practices at the time. I went to every outpatient appointment with H and we had seen Dr Throssel on many routine blood test

appointments. At no point had he ever mentioned that H was infected.

19. Dr Throssel then told us that there was “nothing to worry about”. I think that’s when he mentioned that H was *a carrier* and that he would not suffer any symptoms; and that his liver function was normal. Dr Throssel concluded that the Hepatitis C probably wouldn’t kill H that it would be something else that would instead. He said it can affect the liver but that it was nothing to worry about.

20. I don’t believe that Dr Throssel knew enough about the infection and that I actually knew more about it, due to my medical profession. At the time I worked as Medical Secretary GRO-B at the GRO-B Hospital, in the Department of Haematology. Hence, I was familiar with HIV and Hepatitis C infections.

21. I therefore requested that H be referred to a Consultant Gastroenterologist, Dr Dermot Gleeson. Dr Throssel, conceded to this but gave the impression that in his opinion the appointment would be a waste of time and that I was making an unnecessary fuss. He was a good doctor but he didn’t know enough about Hepatitis C to give any advice about it, at the time.

22. I think that information should have been provided earlier when they found out that H was infected.

23. H s infection was poorly communicated to my husband and I.

24. We were not informed of the risks of passing the infection on to others. However, I followed best practice so I knew the protocols that I had to abide by. I knew that it was highly unlikely that I would become infected from H Of course if you are not medically informed, you wouldn’t know that.

25. To date I have never been advised or taken a test for Hepatitis C.

Section 3. Other Infections

26. I am not aware that H has contracted any other infections due to contaminated blood products.

Section 4. Consent

27. As far as I am concerned H always consented to blood tests. However, we were never told that it was tested for any other purpose or was being tested for Hepatitis C and presumably HIV. These blood tests were never drawn to our attention. We were also not given full information regarding the extent to which he was tested for Hepatitis C, for instance the date when he had first been tested.

Section 5. Impact

28. To the best of my knowledge, H never presented with any physical symptoms of Hepatitis C. Although, it is difficult to make the distinction between his renal symptoms and the effects of the infection; he was always exhausted. We were referred to a Consultant Gastroenterologist, Dr Dermot Gleeson, who conducted an ultrasound of Hs liver. He noted that there was no scarring on his liver and to my knowledge, he never had a liver biopsy.

29. H underwent an operation to remove his parathyroid, which is another symptom of renal failure, this affected his calcium levels and caused him to hallucinate. However, I do believe that his Hepatitis C infection exacerbated his renal condition.

30. Although the mental impact of being infected was much more apparent. For H it was like '*what else are they going to throw at me; I have renal failure and all this other rubbish and now I have this infection on top of it all.*'

31. After H was diagnosed with Hepatitis C he was very bitter, short tempered and a nightmare to live with. He wasn't very tolerant of other people's problems I think he thought that '*I have enough of my own I am not worrying about anyone else*', it changed him a lot.

32. I wouldn't say he was an easy man to live with. He wasn't a generous man or a kind man, but that was down to his ill health. He wasn't like that when I married him, The kidney failure changed him and the Hepatitis C just made him worse. He just kept saying, it wasn't fair on me and I kept telling him that we had to make the best of it. I knew from my job that there were a lot of people worse off than us.

33. It played on Hs mind that he could infect other people, and he certainly did not tell anyone. I remember him worrying if he could pass it on to me, but I reassured him that that wouldn't happen.

34. A further complication, which may be related to Hs Hepatitis C infection, was his hip replacement surgery. The surgeon said that when he commenced surgical intervention, the bone just disintegrated in his hand. This could have been due to his bone marrow not functioning properly, which is regulated by the liver. On this occasion, we did not face any obstacles in accessing this surgery due to his Hepatitis C infection. Although I do remember that the surgery was conducted late in the day.

35. He never received any treatment for Hepatitis C and if he did, I was not aware of any. His liver was not at the stage that required any form of biopsies or treatment.

36. H had to tell his dentist when he went to see them about his Hepatitis C infection but they did carry on treating him. You had to declare it then. Although, I would not have been surprised if they turned round and refused to treat him.

37. H s infective status had various impacts on his renal treatment and it eventually affected his funeral arrangements. Firstly, immediately after we found out that he had Hepatitis C, we were moved into an isolated room for his weekly 4 hour 45 minute dialysis treatment. Previously, when the doctors knew he was infected, but we did not know, we were included in a big room with other dialysis patients.

38. We both enjoyed being with these patients as five hours is a long time to watch someone's blood going round and round. I used to go and talk to people in the unit. I sometimes helped them fill out forms to apply to go on holidays abroad and so forth. When we were separated from the other patients we were never given an explanation, we were just arbitrarily cut off from everyone else. Furthermore, when the doctors knew that H was infected he was using a general dialysis machine, which if good practice is followed, would not result in the infection being spread. When this decision was made we did get asked a lot of questions from the other patients, as to why we were segregated which was an awkward situation.

39. We were also isolated when we went abroad on holiday but they took even stricter measures in relation to his Hepatitis C infection. We would arrive at the hospital at 6:30am to enter a tiny room where I could only stay with him until he was hooked up to the machine and then I would be asked to leave. He was on his own in this tiny room, because of the Hepatitis C; all the other dialysis patients where mixed in together. In this tiny room there was no TV and so it was a very boring process for H to sit through on his own.

40. Another issue that we encountered related to when our home dialysis machine stopped working. On these incidents, the renal unit refused to send an engineer out until the next morning, which was not helpful as H was running his own business and it would severely impact on his work pattern.

41. On these occasions I would drive him up to the hospital to finish the treatment, if a machine was available. However, when the Northern General renal unit were aware of his Hepatitis C status they would tell us that a machine was not available and that they couldn't get an engineer out that night so, can you finish it off tomorrow? Again, this impacted on his work schedule.

42. Over the years they gave us this response perhaps 10 times. A lot of the time nurses would advise me over the phone how to try and fix the machine. They would say, to press this switch or to take that wire or tube out, but I would just refuse, half of H s blood was already going through the machine.

43. On another occasion we wanted to visit his mother, who lived in Paignton, Devon, and had to go into Exeter Hospital to have dialysis. The renal coordinator nurse, in the Northern General, lied to the staff at Exeter saying that H s mother was dying, otherwise they would not have been allowed us to use their dialysis facilities because of H s Hepatitis C. I remember being very uncomfortable having to lie at the time.

44. The worst occasion where the Hepatitis C infection impacted on H receiving other treatment, was related to surgery to remove a cancerous kidney. He originally had polycystic growths on his kidneys, these are a cause of renal failure. The growths are generally hereditary, but H had developed them on his own. The upside of these cysts was that they produced Erythropoeitin- EPO- which boosts haemoglobin production, this is normally dangerously low in renal patients.

45. H had started to suffer from shortness of breath and was referred to a Consultant Cardiologist who performed several tests. We then saw Dr Bruce Huthwaite for, what we thought, was a routine consultation to

discuss the results of the test. However, he said that he had never seen H before, but it looked from H s notes that he had cancer. We were absolutely flabbergasted.

46. Dr Huthwaite said they needed to do some more tests and that H needed to be admitted because his lungs were filling with fluid. I remember that H had a tube coming out if his back to drain the fluid off that was horrible.

47. We were then told that several tests on the fluid were being conducted and to call the Consultant later for the results. They didn't know if this was a renal or cancer issue. When we called they told us that there was no lung cancer. Then we just carried on dialysing and obviously he started to feel unwell again. They did even more tests and said it was a cyst, which had gone rogue in the kidney.

48. The renal nurse, at the time, Tony Smith, said renal cancer was the best one to have because it is contained. So we were told he had renal cancer when he was only in his early 60s.They said we will book you for surgery to get the kidney removed and we were referred to the Oncology Department at the Royal Hallamshire Hospital.

49. In August 2007 we saw the Consultant Oncologist who said he didn't think that the diagnosis of lung cancer made at the Northern General Hospital was correct. Then, at the Royal Hallamshire Hospital they had a multi-disciplinary meeting where they decided that there was no point taking out the kidney as it was a waste of time because in their opinion he already had lung cancer.

50. It was a period of ten weeks between being told that they were going to take the kidney out, to H dying.

51. They did give him drugs to try and slow down the cancer, whilst they tried to arrange a surgery date. The reason this was so problematic

was because of H s Hepatitis C infection. The surgeon told us that due to the infection the theatre was only available at certain times for Hepatitis C patients.

52. I kept ringing and ringing to get a date, but they just kept delaying. I knew that at some point H would be too weak to have the surgery and that's exactly what happened in the end.

53. He went into hospital GRO-B and he died ten days later, on my birthday, GRO-B 2008.

54. I think the Consultant Oncologist didn't want to perform the surgery. I was so angry at the time. I got a letter from him stating that it wasn't his decision that the multi-disciplinary team had decided it wasn't a priority and that the delay wouldn't have made any difference to H s life expectancy. I believe it would have done.

55. I thought I should take this further, but I was so down from H s passing that I decided not to pursue it. This was a huge change for me because H had been such a massive part of my life and once he was gone, I felt that nobody needed me.

56. H s Hepatitis C infection affected his funeral arrangements. I have a good friend of more than 50 years, who is a Clinical Nurse Specialist, GRO-B who worked at the Royal Hallamshire Hospital and the course of her job, dealt with death all of the time. When H was dying she held his hand and tried to make his final moments less traumatic. She also advised me not to go to the funeral home because the undertakers were refused to prepare his body due to his Hepatitis C infection.

57. H always dressed very smartly and he had several beautiful suits. I picked out a lovely suit for him to wear, but the funeral home wouldn't

allow GRO-B or GRO-B to dress him. He was cremated in his hospital gown with his suit laid on top of him.

58. H s social activities fell away when he got sick. When I married my husband he was just a normal guy, we were very sociable and sporty. We had a nice life but when he was diagnosed with renal failure he could no longer ski because he was too tired.

59. H s Hepatitis C infection impacted on our social life because he was always very guarded and never talked about anything to anyone. With renal failure your fluid intake is severely restricted and it also impacts on you socially because your diet was so limited.

60. We used to meet my brother once a fortnight, in a pub but it was always really strained because of H s diet. I think everyone was always glad when the evening came to the end. I must admit my family took a back seat when H was alive, as he found it very difficult to accept them as his family too. He had a very traumatic upbringing, which affected his perception of family life.

61. He eventually became more insular as his illness progressed and the Hepatitis C reinforced this. None of his family knew and he never told anybody at work. He was worried that people would find out and that he would pass it on to me. He was worried about the stigma and how people would react to him if they knew. He also didn't tell anyone about his renal failure, I think because he felt like he was a failure. He just wanted to have a normal life.

62. We never slept together for years due to the renal failure and then the Hepatitis C, just drew a line under it. By the time we got round to think about a family, his kidneys had failed, when he was 39. Instead the focus was on getting H better. Having children became less of a priority and then you just learn to live with it.

63. I never told anybody other than GRO-B because she was involved at the time as a nurse and my boss knew, but other than that nobody knew about the Hepatitis C until H died. I think, I remember saying to my brother when he had died that he had Hepatitis C along with all the other things that had gone wrong. We had a traumatic enough time with his renal failure, without having to discuss the complication of the Hepatitis C.

64. In the end H relied on me for everything. I had to try and keep H in positive spirits. He coped with his illness really well because he had the support of people who cared about him. I had nobody else to complain to, to say what the hell is going on here?, because the buck stopped with me.

65. I remember, on more than one occasion, sitting down on the floor, in corner of the kitchen sobbing my heart out because it was one thing after the other. My parents died a few years before H passed away and I was still working and taking care of H at the time. I had no alternative but to try and stay strong.

66. Had I not been as strong and not worked in a medical environment, where you see a lot of other people a lot worse off than you, I would not have had the mental strength to cope. I used to see such horrible tragic things that it helped me appreciate that we are alive and we had a life (of sorts) which may not be the same as everyone's else's, but we could carry on.

67. During this time, I suffered from very high levels of anxiety and I got shingles. I found it difficult to sleep on my own when H was in hospital as we had a large detached house. As H deteriorated, we decided to downsize and bought a flat in September 2007. I hated this flat because H died on GRO-B 2008, shortly after we moved in.

68. After H died, it took me three months to return to work. I was so down I didn't want to see anybody. I don't know what I would have done had it not been for GRO-B who helped me through it.

69. The impact of the Hepatitis C infection on H's barber shops is difficult to quantify because it created an additional mental burden for him, to ensure that no one found out. Furthermore, he often lamented over several business decisions that he made and later regretted.

70. For instance, he took on a third partner which eventually led to him being pushed out of the business that he had founded. This was while undergoing treatment for his renal failure and whilst he had Hepatitis C.

71. The impact of H's illness affected me in several respects. It stopped me attending golf lessons and line dancing. I started studying for a GCSE because I had not got any qualifications. I did a GCSE project based on my looking after H and I was awarded a distinction for it. But I just had to give it up to take care of H Working in the medical profession was also helpful because people are so much more understanding of your situation. I never wanted to walk around being sad. I only ever worked part-time because I wanted to take care of H as I knew what was coming.

Section 6. Treatment/Care/Support

72. Neither of us were offered any psychological support at the time of the diagnosis.

Section 7. Financial Assistance

73. We received a one-off payment for £20,000 from the Skipton Fund some time between 2003 and 2007. I remember requesting Dr David Throssel to write a letter of support.

74. However, I didn't hear anything for quite a while so I then decided to get in touch with the Hepatitis C campaigner Paula French. I read one of her newspaper articles and she gave me some advice. She recommended that I have a face to face meeting with my local MP Clive Bets. Once, we spoke to him things then progressed very quickly.

75. H decided to accept the £20,000, even though he knew some people received significantly higher amounts. H knew he didn't have that much longer, because of the renal failure and Hepatitis C. He didn't think he had the fight to keep going or to live long enough to get a higher amount.

76. H had to waive his rights to pursue his case further as a precondition of accepting this compensation.

77. We only ever had that one payment. We didn't receive any ongoing payments, apart from the Disability allowance.

78. There was a lack of communication in relation to financial assistance that we were eligible for. Nobody ever gave us advice on the matter. There was a social worker assigned to the renal unit in the Northern General Hospital but we never felt they were very helpful.

79. No payments were made directly to me.

Section 8. Other Issues

80. To date I have not been part of a campaign or any litigation.

81. On H s death certificate, it notes that he died on the GRO-B 2008 which was caused by I. a). Carcinomatosis and b). Right sided Renal Carcinoma as well as II. Hypertension. (exhibit **WITN0507002**). The term carcinomatosis implies that multiple carcinomas developed

simultaneously, throughout H s body. I was not aware of this condition until I read H s death certificate.

82. I did try and obtain H s medical files but I was told that as it had been over 10 years, they had destroyed his paper records but that they were still on microfilm somewhere.

83. If I was to pose a question to the inquiry, it would be to the people involved with blood transfusions and blood products at the time. I would like to ask why did they continue to bring in contaminated blood products? When there was substantial evidence at the time indicating the dangers?

Statement of Truth

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

Signed GRO-B

Dated 8/8/2019