Witness Name: GRO-B
Statement No.: WITN0148-001
Exhibits: WITN0148/002-007
Dated: 16 October 2018

FIRST WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 11 October 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference

I, GRO-B, will say as follows: -

Introduction

1. My name is GRO-B. My date of birth is GRO-B 1970 and my address is known to the Inquiry. I live with my wife GRO-B whom I met in 1997. I work as a Psychotherapist and Counsellor in London. I intend to speak about my life having contracted Hepatitis C. In particular, how I came to be infected, how the illness affected me, the treatment I received and the impact it had on my life.

How Infected

2. I was infected with Hepatitis C via blood transfusions that I received at St Helier Hospital between February and May 1990 when I was 19 years old. I was admitted to hospital with pneumonia and this was complicated by septicaemia, which resulted in multiple organ failure. In total I received 137 bags of blood.

St Helier Hospital

3. I was admitted to St Helier with pneumonia and was extremely unwell. I was told that I had become ill as a result of living a very hectic lifestyle and that the pneumonia was a result of being "rundown". However, I was so unwell that I was put into an induced coma.

4. I have learned from my medical notes that whilst I was in a coma I was given numerous blood transfusions. I have copies of the labels from the 137 bags of blood that I received. I exhibit this documentation as **WITN0148/002**.

5. I have been told by one of the nurses that looked after me that the doctors and nurses couldn't understand why I was so ill. Up until this point, I had been a fit and healthy 19 year-old and there was no obvious cause for the severity of my illness.

6. When I eventually came round from the coma I weighed six stone and soon became ill again; my blood count started to decline and the infection came back. My condition had deteriorated to the point that my parents were called to the hospital in order to say goodbye to me. My father was asked to turn off my life support machine, however, he refused to do so and that night my blood count went up a little for the first time.

7. Despite this, a persistent infection in my right lung (middle lobe) meant that part of it had to be removed. On 6 April 1990, a surgeon from St Georges Hospital came to St Helier to operate on me. As I was prepped to go into surgery I was terrified. I was taken out of my care bed and on to a stretcher with drains and a manual ventilator coming out of me.

8. I stayed in hospital whilst I recovered from surgery and slowly built up my strength. I eventually got rid of the infection.

9. Neither I, nor my family, were ever advised of the possible risks of infection from the blood transfusion as I was in a coma at the time.

Diagnosis

10. Following discharge from St Helier, I went to the South of France to take some time out and recover. My time in hospital had shaken me and I began defining myself by the fact that I almost died.

11. Eventually I returned to the UK and focused on building a happy life; I got a job and met GRO-B in 1997.

12. By 1999, my relationship with GRO-B was becoming serious and we moved in together in Tooting. I registered with a local GP, Dr Shiraz.

13. I saw Dr Shiraz reasonably regularly because I had a high blood pressure that needed medicating. This had developed after my hospital admission in 1990.

14. On 8 March 1999, during an appointment with Dr Shiraz, she advised me that there was a blood pressure research project taking place at St George's Hospital which I could take part in. Dr Shiraz said that this would be useful as the research project might identify why I was suffering from high blood pressure at a young age.

15. I therefore joined a research project on salt, diet and high blood pressure under Professor McGregor. The research involved regular blood tests and

it was through one of these tests that it was identified that I had Hepatitis C antibodies.

16. I found out when I received a voicemail from Dr Phil Rice sometime in early August, while I was at work. In the message he said that he was the consultant virologist from the Haematology department at St George's Hospital and asked me to give him a call back. I phoned him back and he told me that they had found HCV antibodies in my blood. I asked him what that was. His response was "oh, you didn't know? You better come round and I'll talk you through it.'

17. I saw him that afternoon at St George's Hospital. He picked me up at the reception and he talked me through what HCV was and informed me I would need to take a specific HCV test. I was terrified. It brought up all my past memories of being in hospital and was a very traumatic experience. For this reason, I don't recollect much of what he said to me or the advice I was given, but I do remember that I asked Phil Rice how Hepatitis C is transmitted. Dr Rice went through the possible causes, including blood transfusions. At this point I said that I'd had blood transfusions. Phil told me to tell my girlfriend (GRO-B) to get tested and I was advised to stop drinking. Conversely I remember being told by Sister Lee that I didn't need to give up drinking but that I should just drink less.

18. I remember that during this meeting I felt that whenever I had hope for the future something awful would happen and I would be forced to confront my own mortality. I felt that I was not allowed hope.

19. We weren't told much. Most of the things we know such as to use protection during sex we read up about ourselves. We were lucky that we were so capable and able to look into it ourselves. For example, we knew we had to bleach the surfaces thoroughly if I was ever bleeding because the hepatitis C virus can survive in dried blood for up to three months. However, there was no education around these precautions, we had to find out for ourselves. About a year after my diagnosis I remember that I did get a leaflet on HCV from Sister Lee.

Other Infections

20. I did not contract any infections other than HCV as a result of my blood transfusions.

Consent

21. I do not believe that I was treated or tested without knowledge, or for the purposes of research.

Impact

Treatment

22. After Phil Rice advised me that I had HCV antibodies I was moved from the hypotension clinic to the liver clinic. I was diagnosed on 22 June 1999 but not referred to the liver clinic until October 1999.

23. After the initial diagnosis, I was just waiting and waiting to hear back from the liver specialist. Nothing much happened for quite some time. I was having frequent nightmares while I was waiting. GRO-B told me that I shouldn't wait any longer and persuaded me to chase the specialist to follow up. Eventually I did so; at which point I was told by the hospital that my file had been lost.

24. Consequently I didn't have a liver biopsy until February 2000, 8 months after my diagnosis and 4 months after being referred to a liver specialist.

25. The treatment I was seeking was the interferon, which involved injections 3 times a week. At this time pegylated interferon was available and more effective, but it was also more expensive and so they gave me the cheaper treatment instead.

26. GRO-B has reminded me that there was a big drama about which pharmaceutical companies would be used when the treatments came out. There were two main companies manufacturing treatment for HCV. One of them had a much better product

27. Originally I had Interferon injections and the Ribavirin pills together. The injections went in my tummy or legs. I learnt to inject it myself straight away. It wasn't always easy, if I hit a blood vessel when injecting myself it would be really painful. The first night of my treatment I was shivering and felt severely nauseous. Interferon is a protein and therefore the body "eats up" the protein in a patients' system. However, the really nasty drug is Ribavirin, which I took twice a day (in the morning and evening). It's like a poison and. it seized my back up. I also developed muscular pain and was extremely lethargic.

28. While I was undergoing the first course of treatment I was working for Sky GRO-B I had the first few weeks off on sick leave when I first started the treatment. The company were amazing and very supportive. I decided to try and continue to work for some degree of normality. Sky allowed me to go in any time I liked which was essential because it could take me hours to get out of bed and as a result I would occasionally get into to work as late as eleven, or twelve o'clock, do some work and leave at three or four o'clock. My colleagues didn't really understand what was going on but they were nice about it, as were a few friends.

29. I just wanted to get on with my life. GRO-B and I would still try and go to the theatre but life revolved around the treatment. Once, I had to inject myself at the theatre, and felt like I looked like a junkie. I couldn't drive due to paralysing waves of nausea. The nausea was cumulative so as the year went on I got more and more ill. I developed skin rashes; all over my legs and so was itching all the time. It was unpleasant and uncomfortable; I would describe it as an internal un-comfortableness all day.

30. I was vomiting in the morning and experienced aching and nausea all the time. I lost my appetite and suffered from mood swings and insomnia. I didn't get any sleep for a year. I was always hungry but couldn't eat. One morning I was retching and vomited up all my pills and then had to pick them out of my vomit and eat them again because they could not be wasted.

31. The most disturbing effect was depression. I experienced a complete sense of doom. By nature I am a proactive person, I like comedy, and try to find the good in the bad times. I had never experienced anything like it; such a dark mood, I just felt a sense of doom. Although I was never suicidal my whole character changed. I was constantly sad and anxious, lethargic and fearful.

32. GRO-B recollects that our lives just revolved around my injections. We were newly weds and it should have been a happy time, however my treatment destroyed that year. GRO-B recalls us travelling to Lisbon for our first wedding anniversary but I was too ill to enjoy the trip as a result of my treatment. I was sweating and green and we had to go back to our hotel room. GRO-B said she felt awful because we had gone away and I was so ill.

33. My treatment lasted a year. When it had finished I had to wait forever to get my test results as the tests were only sent off at certain times. I received a letter on Friday 3rd May 2002, which said, 'GRO-B has relapsed". Effectively the letter said that I was not cleared of Hepatitis C and that my only hope was to get a liver transplant but the HCV will destroy a new liver twice as fast as my own liver.' The news was devastating.

34. At this point I was being monitored and treated by Professor GRO-C who was the Consultant Gastroenterologist at St George's Hospital. We were all well aware of pegylated interferon at this time, which Professor GRO-C wanted to try in another round of treatment. He was particularly concerned, because the HCV had come back aggressively.

35. I had to wait another year and try and get funding. Professor Tibbs was on board with me receiving more treatment, but at that time the policy was that patients would only receive one round. Professor Tibbs basically said he would find a way and so I fattened myself up and prepared my mind for next round of treatment.

36. Statistically, the first time round I had about 30% chance of the treatment being successful, By the second time round, pegylated interferon had a much better success rate of about 60%

37. The first time, I had pushed myself through, but the second time round I decided to do it a different way. I still worked though. Nobody can believe I did it twice. I would go to a hepatitis support group and the other members would always be surprised when I said that I was on my second round of treatment,

38. The second time round was better and after about 2 weeks the pain in my back started to alleviate and I remember thinking "oh my god I'm starting to feel better". I finished the second round of treatment in 2004 and got cleared for HCV again. Nine months after the second treatment I got an all clear for the second time.

Stigma

39. Being infected with Hepatitis C made me feel poisonous. I remember going for a wet shave with a group of friends before one of them got married. While we were there I suffered a nosebleed. Blood was all over my shirt and the barber went to go fetch a towel. I had to say "no, I am poisonous don't touch me". They kept saying, "no, no, no, we will take care of it" and I kept saying, "you can't touch me or my clothes. Everything needs to be incinerated". And I had to do this in front of my old school friends.

40. GRO-B recalls a time that we went round to see an old girlfriend of hers and her husband refused to shake my hand.

Treatment/Care/Support

Difficulties obtaining Treatment

41. Professor Tibbs first treated me at the liver clinic on 9 December 1999. He was amazing. He said that they would like to treat me but that they didn't have sufficient funding for the treatment. The rules in those days were that you had to have a certain level of damage to your liver to receive treatment. As I had discovered my diagnosis early by accident, I didn't have sufficient damage to receive treatment.

42. I was a 30-year-old fit and healthy man who has been lucky enough to be diagnosed early in the development of the disease, but that didn't qualify me for treatment. At this point, I had given up drinking, and did all I could to save my liver.

43. There was then a period of me fighting to get treatment. I tried to get funding for the treatment by tracking down the relevant people who could help. On 18 August 2000, I wrote to my MP, Tom Cox, informing him that I needed Interferon and Ribavirin, which although not approved in my area, would have been available if I was based in Kingston. I exhibit this letter as **WITN0148/003.**

44. Tom Cox sent my letter on to Sue Gallagher who is the Chief Executive of the Merton and Sutton Health Authority. She replied that trials had established that Interferon and Ribavirin are effective but the Merton and Sutton Health Authority didn't have funding for it. I exhibit this letter as **WITN0148/004.** Once I received that letter from Sue Gallagher I wrote back to Tom Cox asking if that meant that I could have the treatment in theory but there was no money available for it. I exhibit this letter as **WITN0148/005.**

45. It was then that Dr GRO-C stepped in and effectively said, "stuff this, you're young, it's a blood transfusion, you've stopped drinking, you're doing everything you can, I am going to give you this treatment anyway." My understanding is that he must have done this through creative accounting and did not actually have authorisation to give me the treatment.

46. My name got to the top of the list for treatment for lots of reasons and GRO-B and I have both experienced some guilt over this. I am articulate, I can put an argument together, but I am also charming and polite. I had my wife supporting me, and Dr GRO-C on my side. This enabled me to essentially bully my way to the top of the list for treatment. I received treatment over people who were, perhaps, less articulate than I was, and had fewer resources available to them.

Counselling and Support

47. In terms of counselling and psychological support, GRO-B was extraordinary throughout the whole thing. I remember making her cry once as I was being monster to her on the train as a result of the drugs I was taking. We were newly married at the time. She questioned whether the person I had become was the man she married, thinking, "is this the man I married or is he simply suffering from the side effects of the drugs?"

48. She was incredible throughout the whole thing, always looking things up online that might help me. For example she found me a hepatitis C support group to attend however, the issue with this was that all of the others members in attendance were drug addicts and so I still felt quite alone, and like my experience was unique.

49. I received support from Sister Lee who at one appointment had said: "I've got a counselling qualification why don't you come and see me." She wasn't employed at the hospital as a counsellor; it was all extracurricular

for her. I saw her every two weeks, which was good and helped. She offered me anti-depressants but I didn't take them.

Financial Assistance

50. I wasn't told about the Skipton Fund. GRO-B was on the Internet and she found out about it on there. I was heavily involved with the Hepatitis C Trust at this point so I was probably also made aware of it through that.

51. There was a bit of an issue when I initially applied as the first ever record of me having had a transfusion came to light in 2001. GRO-B encouraged me to request my medical records when Leigh Day were bringing their class action. She thought there was something fishy going on and mentioned the class action to me. I didn't want to get involved as I just wanted to concentrate on getting better, but she suggested I request my medical records in case I wanted to pursue something later. It was approaching the 10-year mark where my records would no longer be retained and so I decided that I should obtain all of my medical history.

52. When I contacted the hospital for my records, by chance I knew the woman who was dealing with my request. She said "you're lucky as they should have been destroyed three years ago but we actually still have them." I paid the fifty pounds to obtain my records, which included evidence of my blood transfusions.

53. This was particularly significant because before I applied to the Skipton Fund, I was advised in a letter by Dr Patricia Hewitt (a consultant haematologist at the South London Blood Transfusion Service) that there was no evidence to suggest I had ever had a blood transfusion. I exhibit this letter as **WITN0148/006.**

54. In light of this, when I applied to the Skipton Fund I supplied photocopies of my medical notes showing I had been given several blood transfusions. Professor GRO- supported my application and wrote a letter on 5 October 2004 to Dr Hewitt advising that I had in fact had multiple transfusions in 1990 and enclosed my medical records as evidence. I exhibit this letter as **WITN0148/007.**

55. My application was accepted on 4 November 2004 and I received a £20,000 ex-gratia payment. I recall the payment came through fairly quickly. I also recall it was very difficult to sign the piece of paper required as they made you agree that you would never bring any other type of claim. If you signed the agreement it was null and void, you could never bring further action.

56. Up until this point I had been very fortunate to still be working for Sky who were very kind. They paid me full pay for the 2 years while I was receiving treatment. However, I resigned when the funding from Skipton came through. I used the money to do my diploma in counselling at WPF

Therapy. I trained for three years, which was excruciating and then set up a private practice at GRO-B. The last year of my diploma I took up psychotherapy as an extra qualification. In total my training took 4 years and I had 2 Masters degrees at the end of that. The money that I had received from the Skipton helped me fund my study and the Hepatitis C Trust paid my tuition fees.

57. On 19 June 2017 I started to receive stage 1 payments from the Skipton Fund; my first payment was backdated for April, May and June. The total payment I received was £3030 a year.

58. I now receive £333 a month from the Skipton Fund but it just changed the rules for people who have suffered from the side effects of Interferon. I was very recently sent a letter, which listed side effects and informed me that if I suffered from any of them, I would qualify for the new special category mechanism, resulting in a higher annual payment of £15,655. Upon receiving this, I went back to my GP and said, "I don't want to try and get the extra money but I do want to know if I have any of these other issues". Fortunately, I don't.

59. In addition to the Skipton Fund payments, I receive an extra £519 winter fuel allowance and free prescriptions. I feel funny about it, because I don't have Hep C anymore.

60. In June 2018, a review of the funding schemes was undertaken and changed from EIBSS.

Other Issues

61. I have an on-going emotional quandary because the blood that saved my life was also the blood that was killing me. I just haven't squared it in my head. It's such a weird feeling. I wouldn't change it. If I was lying in bed again at 19 dying of pneumonia and someone said to me if "I give you this blood now you won't die but it will kill you in 20/30 years time" I would do it again.

62 GRO-B reminded me of an incident with GRO-B She was a specialist nurse but also had a higher up role at St George's. When they promoted her she still wanted to keep hold of her clinical work. She only accepted the job on that basis. When we were talking to her, GRO-B said "now that you know GRO-B has got it from a blood transfusion would you not want to try and go back over all those bags of blood and try and trace those back?"

63. She was incredibly defensive and she said, "no we don't do that". GRO-B said "oh that's ridiculous as there's all those other people who could be infected that you could contact.' She was very dismissive of this and

defensive. So thinking back that seems very odd and her reaction was suspicious.

64. Similarly, when Dr Patricia Hewitt wrote to Professor Tibbs on 5 May 2005, acknowledging that I had received a blood transfusion, she also advised that no investigations into the donors of the blood I was given would be conducted. She explained that was because more than 15 years had elapsed since the donations were given and that if any of the donors had returned after the introduction of routine screening in September 1991, they would have been identified and a Lookback carried out for recipients of previous donations. She therefore concludes in her letter that as I was not identified through the hepatitis C Lookback, it can be ‘assumed’ that that if any of the donors were infected with HCV, they had not returned to give blood.

65. Furthermore, when I was working on this statement with members of the inquiry team, it was brought to my attention that the letters sent to my GP following my discharge from hospital in 1990 provided a narrative of the treatments that I had received but did not note that I had received blood transfusions. This means that my GP would never have known that that I had transfusions and therefore would have probably not considered me to be at risk of Hepatitis C. I am extremely surprised about this and very concerned, particularly when I consider that in addition, the hospital denied that I had blood transfusions at one point.

Statement of Truth

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

GRO-B

Signed ______________ GRO-B

Dated 17th Dec’18