ANONYMOUS

Witness Name GRO-B
Statement No: WITN0616001
Exhibits: Nil
Dated: 27 March 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 18th January 2019.

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

Section 1. Introduction

1. My name is GRO-B. I was born on GRO-B GRO-B 1980 in GRO-B. I am an unemployed man living in Cornwall with my wife and our 3 youngest children. We have 5 children in total, aged 25, 24, 15, 14 and 7. The eldest 4 children are from my wife's previous marriage and the youngest is from ours.

2. I am not legally represented and I am happy for the investigators to take my statement. I also wish for my identify to remain anonymous. This is for both personal and family reasons.

3. I intend to speak about my infection with Hepatitis C. In particular, the nature of my illness, how the illness has affected me, the treatment

received and the continued impact it has had on my wife and I, and our lives together.

Section 2. How Infected

4. I have two tattoos and a piercing, however I got these after I was infected with Hepatitis C.

5. As a child, I grew up with my parents and younger sister in GRO-B. Mum was a housewife and Dad held a couple of jobs. I now have 2 younger sisters.

6. Between 4 and 6 weeks before my 9th birthday, I had really bad tonsillitis and had to have a tonsillectomy. My tonsils were so swollen that the doctors thought that I had a tumour. I had the tonsillectomy at GRO-B District General.

7. I later returned to the hospital to get the results of the tonsillectomy. I remember my dad had bought me a packet of Cadbury's chocolate fingers and I sat in the hospital corridor eating them whilst my mum and dad went into a room with a doctor.

8. Mum and dad came out in tears. They were absolutely beside themselves and I didn't have a clue what was going on.

9. I was then taken into a room and told that I wasn't allowed to eat. Everything nosedived from there.

10. It is all a bit of a blur and I must say now that I have no memory of dates and when things happened both back then, and even more recent events, my memory fails me.

11. I do remember being taken to GRO-B Hospital. I don't remember much about arriving at the hospital but I do remember being in a bed, having a Hickman line and thinking, "what the heck is going on here".

12. Someone then explained to me what happening. I still didn't really understand. I had never heard of cancer; never heard of it, why should I? I was a young lad.

13. They first explained that I had B-Cell Acute Lymphoblastic Leukaemia. I had never heard of it. They then said that it was cancer. I said, "What's that?" They then explained that I might not make it through many more nights. That scared the living daylights out of me. I was petrified to go to sleep in case I didn't wake up. I did my best not to fall asleep, as I was frightened of not waking up.

14. I didn't know what a tumour was at that age. I basically didn't have a clue. I felt fine, really no different to how I feel now.

15. This type of Leukaemia was rare in adults and kind of unheard of in children. The doctors therefore wanted to take notes on how I was responding to treatment etcetera and so mum and dad had to sign forms allowing them to do so.

16. GRO-B Hospital was fantastic in all fairness. I had blood transfusions, chemotherapy and was given platelets. I started to get better and eventually went into remission. Everything was fine. Everything was brilliant.

17. When I was still recovering from the Leukaemia I was invited down to GRO-B, Cornwall, to a GRO-B It was fantastic. I flew in a helicopter and really enjoyed it. Mum and dad said, "If you make it, which we are really sure you will, we will move to the coast". I thought, "Great, that's something to look forward to"

18. We moved to GRO-B when I was 13 or 14 years old, in the bleakest of winters. I hated the place at first, but I grew to love it.

19. As a child, I always felt tired. Where a lot of my friends could run around for a long time, I could only run for a short time and would have to sit down after. I didn't think much of it. I just thought this was normal for me. Particularly as I was recovering from the Leukaemia.

20. Then one day, mum was watching a programme related to Hepatitis C and people being infected through blood products. Following the Leukaemia, she was an over-protective mum. If there were any tests going, I would be in for them, whatever they were. I used to joke to her and say, "I am not your pin cushion"

21. I remember being driven to GRO-B for what I now know was the Hepatitis C test. We went into the haematology and oncology clinic and I had the test. I didn't really know what it was for, mum didn't really tell me. The doctor assured us that I was probably fine.

22. It wasn't long after that it turned out that I had been infected with Hepatitis C from one of the many blood transfusions I underwent at GRO-B GRO-B Hospital. I was angry like I never have been before and doubt I ever will be again. I was with my mum when the doctor told us. I just remember thinking that this was really serious.

23. No information or guidance was given to my parents or myself about living with Hepatitis C. When I realised what it actually was, it was almost a case of the blind leading the blind. Anything that I found out was through 'Dr Google'

24. I was later told that it could be passed through sharing toothbrushes and sneezing. At this point, all I could think was, "Oh my goodness, the amount

of times that I have cut myself and people have helped me, how many people have I infected?" I hated the realisation and impact it could have.

Section 3. Other Infections

25. I do not believe that I have received any infection or infections other than Hepatitis C.
26. I tested negative for HIV around the same time that I was tested for Hepatitis C. I was petrified of that.

Section 4. Consent

27. I don't believe that I have been treated or tested without my consent. Since I have been old enough to consent, I have always consented to tests. Before this, I assume that my parents did.

Section 5. Impact

28. Being infected with Hepatitis C has affected me physically and mentally. Whilst I know that it happened, sometimes I feel like it never really did. It is surreal.

29. Physically, I have suffered with severe lethargy and memory loss. This impacts upon my family life because I can't do the things that I would like to be able to with them.

30. My youngest son loves to play football. I can kick the ball for him but that is it. I can't run around after it with him like I would like to. My energy levels are just too low.

31. Similarly, I couldn't get involved in school Sports Day with my two girls. Every year, there was a parent's race. I would watch my wife run and feel proud, but I would be thinking, "Oh no, it's the dads next". I could never take part and the girls never really understood why.

32. One year I did join in. I came last by a long way but it made the girls happy and they were cheering me on. I paid for it for about 2 weeks afterwards. I couldn't get up the next day. I was dead to the world. I was in so much pain.

33. The memory loss is just as bad. I need to keep being reminded of things. I couldn't even remember what time you [the Inquiry team members] were coming to take my statement today. I'm glad you called the day before to remind me.

34. I also suffer with 'brain fog'. For example, when filling in forms I can't remember things that I should know. I even forget my children's dates of birth. This really upsets me. There have been times when my children have realised I don't know their date of birth, and this upsets them too.

35. Mentally, it has been a constant strain and worry on my mind. I can go for days without thinking about the fact that I had Leukaemia, whereas I can't even go for an hour without thinking about Hepatitis C. I hate myself. I absolutely hate myself. It is just constant turmoil and it won't go away. I have never felt suicidal, but it is the constant fear of "What if". My main fear is of infecting someone else. This is a fear I lie with every single day. I hate the word, but I do feel very paranoid.

36. If the children cut themselves, I can't deal with it. I let my wife help them or take them to the doctors. Similarly, if I hurt myself and have to go to the doctors to be patched up, I get paranoid that I will infect the doctor.

37. If go to use my toothbrush and it is not where I left it, I get paranoid and put all of the toothbrushes in the bin. This happens about once a week. I know that there would need to be a large blood loss to risk infection, but I am overly cautious anyway. I could never forgive myself if I infected my family.

38. When my youngest son was born, I was petrified. He is like a little carbon copy of me and he does so many things that I remember doing when I was his age. This similarity makes me paranoid. I am scared that he is going to end up with Leukaemia. I am also scared that I have infected him with Hepatitis C. I am so worried about this that I can't even bring myself to have him tested. Part of me wants to check, but the bigger part of me doesn't because if he was, I couldn't live with myself.

39. I went through a little patch where I was thinking about it so much that I kept scratching myself. I did it so much that I got terrible sores on my arms.

40. One day I would have been about 18, I was sitting down somewhere, maybe waiting for a bus. I saw a woman nudge her husband and point at my arms. It was obvious that they were having a conversation about me, so I said to the woman, "Can I help you?" She looked over and said, "You are disgusting". She thought that I was a drug abuser. I have never even smoked, let alone taken drugs. I have the occasional glass of wine but that is it.

41. Even now, I understand that there is nothing left of the blood that had been given to me; my body has processed it all. I am however left with the Hepatitis C going around in my blood that isn't me. A side affect of the virus is that I itch really badly. It is horrid I itch all the time.

42. Further medical complications have resulted from my infection with Hepatitis C. I have cirrhosis of the liver, however it isn't too severe. I also have heart problems and take two forms of medication every day: Lisinopril and Amlodipine.

43. I have had multiple liver biopsies. I had to go to Kings College hospital a couple of times. I remember one time the staff were preparing my mum for administering my treatment at home. I am not sure which treatment this was. I remember watching her practicing on an orange and thinking, “oh God, she is going to kill me if she does this”.

44. The last time, I was about 15 or 16, I attended Kings College hospital I had tests and a liver biopsy. The doctor came in and was ecstatic. He was absolutely ecstatic. I wondered what on earth was going on. He then told me I was clear of Hepatitis C. I remember thinking that this was a bit contradictory, as I had previously been told that I had it for life.

45. I went home and everything was fine again, but the lethargy didn’t go away.

46. From the age of 17 to my early 30’s I thought that I was clear of Hepatitis C. However, in my early 30’s I was in GRO-B which is a shop in GRO-B with my wife and I found a big lump on my side. I went to the doctors and he took blood samples and sent me to hospital. The lump didn’t turn out to be anything bad. However, the blood tests taken at GRO-B GRO-B surgery came back and showed that I still had Hepatitis C. I was absolutely gutted.

47. I have since received Interferon treatment for my Hepatitis C infection. This involved an injection, once a week, for 12 months. The course finished 6 years ago.

48. My wife was heavily pregnant when I first had Interferon. One evening, she was sleeping on the sofa and so I decided to do the injection myself. I prepared it and went into the living room, but I couldn’t bring myself to do it. I tried for so long, but I couldn’t get it anywhere near my stomach. I was sweating and in tears.

49. There is a time limit on when I must administer the drug and I had no choice but to wake my wife up for her to injected me.

50. The Interferon made me feel terrible. I was always tired and felt like I had the flu and couldn't shift it. I had headaches and felt sick. It was horrible. Some of the injections made me feel terrible straight away, whereas others wouldn't until the following evening.

51. I also ached constantly and I still do. I can't get comfortable in bed and I hurt so much. As I said before, I also still itch.

52. Whilst on treatment, I had another biopsy. I hated the biopsies. I was in a room with 2 other guys, an alcoholic and a drug abuser. They were completely out of it. There I was, again surrounded by people like that. I understand that I have been quite judgmental, but I was a child when I got infected, whereas those men were likely to be self-inflicted.

53. As it stands at the moment the Interferon did not clear the Hepatitis C, but it put it down to an extremely low level. I have not been told of any new treatments.

54. Hepatitis C has impacted upon my private, family and social life, so much so that I pretty well kept my self to myself.

55. The biggest positive change in my life was when I met GRO-B 9 years ago. We were friends at first, but I had been instantly attracted to her. I was scared of telling her about the Hepatitis C for the fear of rejection.

56. I eventually blurted it out one day when we were out walking and she just said, "okay" and carried on walking. I instantly regretted telling her and felt crushed. She then turned and said, "Are you going to stand there all day". I said, "Did you hear what I said?" She said, "yeah, and I told you I had 4 kids and you didn't run".

57. I couldn't believe it. I was overjoyed. This soon turned to panic and anxiety. A couple of days later we had our first kiss and I was worried that I had infected her. I was worried that she would go home and kiss her children and infect them too. My anxiety was set off again.

58. We wanted to have children. I didn't think that I would be able to conceive due to my history of illness, however we did and my wife and I had a baby boy together. He is bundle of incredibleness.

59. As previously mentioned, I am constantly paranoid about infecting my wife and children and this impacts my daily life with them.

60. It also impacted upon me as a young man. I avoided relationships because I knew that as soon as I told them about Hepatitis C, they would have disappeared. It is a natural reaction I suppose. I probably would have done the same.

61. My parents live nearby in GRO-B, however we have drifted apart. The family support isn't there and I don't speak to them often. I often feel isolated. I don't know if this is why, but mum was pregnant when I was in hospital with Leukaemia. The pregnancy wasn't going well and she said, "God if I have to lose one, let me lose the one that I have not met". She miscarried and lost the baby.

62. She fell pregnant again and they have since had another baby. They only seem to have time for my youngest sister. She has some sort of princess status. I had to tell my mum about the damage to my liver and her response was, 'well you have had a good innings' There was no empathy from her. GRO-B and I half expected her to call back when the impact of what I had told her has sunk in but she never did.

63. I think even I am not that different to a lot of people in the sense of stigma and stereotyping. As soon as I see HIV, I associate it with drug abuse. I

think that is what people see when they see Hepatitis C now too. It was always linked to drug abusers in the news, which didn't help.

64. The stigma surrounding drug abuse is definitely the main issue. People assume I am a drug abuser and that really bothers me. I would never take drugs.

65. I try to avoid suffering from stigma by not telling people about my infection. My neighbours don't know. They don't need to know. The few people that do know, know because my mum told them. She thought she was protecting me by telling people, but it didn't work out that way.

66. I am afraid of people finding out, in case my children's friends find out and they become alienated and ostracised, as I was. I don't want them to have to go through the same thing.

67. When I was at school, I always wanted to join the Army and become a sniper. I have always been quite effective with things such as catapults and air rifles. I wanted to join the Army so badly.

68. I had been talking to a recruiter about this at a school fair, and things were going brilliantly until I mentioned that I had had Leukaemia. That was that door closed. He effectively said that I was too much of a risk.

69. Looking back, I wouldn't have lasted long anyway due to the Hepatitis C. My energy levels would not have suited the active Army life. I would have failed at the first hurdle.

70. Having been told that I couldn't pursue the only career I was interested in, I lost interest in school. I was also working part-time in a local butcher shop, which I really enjoyed.

71. I left school at 16. I then decided that it wouldn't hurt to better my grades, so I went to college. I enjoyed college, but I preferred working in the butchers.

72. The butcher I worked with offered me an apprenticeship, so I took it. It was great. I was being paid weekly and was able to move out and rent my own house near the shop. For a while I really enjoyed the work. However, the butcher later started engaging in practices, which had been banned as a result of the vCJD issues, selling meat on the bone etc. I didn't agree with this and I resigned. Unfortunately he passed away shortly after.

73. I then got a job as a pot washer, however when I found out that I still had Hepatitis C and disclosed this to my boss, I was laid off. I understood this and it was amicable. I appreciated that even the hospital had told me that I shouldn't be working in a food environment.

74. There weren't a lot of job opportunities that didn't involve food in Cornwall, so I moved back to GRO-B. I rented a bedsit that provided me with everything I needed and signed on. I felt that his was a positive turn around. I had my own base and a permanent address that I could give to potential employers.

75. I attended interview after interview after interview. They went well, however as soon as I mentioned Hepatitis C that was it. Employers were no longer interested. One time, a lady at the employment centre, physically moved her chair back when I mentioned my Hepatitis. I asked to speak to her superior, and she did pretty much the same thing. This is the normal reaction I receive.

76. I was accused of not trying hard enough in the interviews and not trying hard enough to find a job. This wasn't true. I was attending interviews all over the place. It was the Hepatitis C that was the problem.

77. On a couple of occasions my job seekers allowance cheques stopped coming in the post. I went into the job centre and enquired about it. They said that I had been cashing them in and accused me of trying to fraudulently claim more. This angered me. I knew I hadn't. Someone else was forging my signature.

78. I left soon after and hitchhiked back to Cornwall and have been here ever since. At first, I moved back in with my parents and did odd jobs to keep myself busy. This was horrible as I felt like I was putting on them.

79. I then signed on again and managed to rent a caravan in GRO-B. I had the same issue with interviews, to the point at which one man asked me if I had considered moving to somewhere where no one knew me. This made me so angry. In the end I gave up and signed off.

80. It is not cheap having 5 children, and just before the Skipton Fund started making regular payments I was suffering badly with depression due to the fact that my wife was doing everything. I became a recluse and didn't like going out or answering the phone. I did all my shopping on line in the knowledge I would only have to deal with one person at my door. It really bothers me that I don't feel as though I am supporting my family.

Section 6. Treatment/Care/Support

81. I was never offered any counselling or psychological support in consequence of being infected.

82. If I had been, I probably would have turned it down through fear of judgment and confidentiality being breached.

Section 7. Financial Assistance

83. Accessing financial assistance was straightforward. My Hepatitis nurse gave us some paperwork to complete and this was sent off. I am not sure when this was, but it was within the last 9 years.

84. I received a lump sum payment of £20,000.00 from the Skipton Fund. I used this to pay off my wife's debts from her previous marriage. In addition to this, I receive winter fuel payments in December of £500.00

85. I also receive two monthly payments; one at the start of the month and one at the end. One of these is a special category mechanism payment of about £1,500.00.

86. Finally, I receive an income top-up amount to help with the children.

87. The money helps to keep our heads above water, but I would rather have my health back. I want to be the dad that runs around with his children and has the pictures of himself doing activities with his children. I don't have that because I am physically incapable.

Section 8. Other Issues

88. Aside from being infected with Hepatitis C, I am eternally grateful that the Leukaemia treatment saved my life. There was quite a patch when I wasn't, but I am now.

89. Now, it is not about trying to forget about the Hepatitis C, but about trying to find a way to put it to the back of my mind and continue with life.

90. I wanted a medical necklace stating that I had Hepatitis C, so that I could warn people if ever I was in an accident. I wore it to walk from my house to

the car and then immediately took it off. I felt as though I had physically labelled myself.

91. I really want to know why the blood I was given was not tested for diseases; did they know there was a risk? Did the Government know and did they allow this to happen to save money?

Statement of Truth

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

Signed GRO-B

Dated 27/03/19