Witness Name: GRO-B
Statement No.: WITN2200001
Exhibits: **None**
Dated: 20th December 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5th November 2018.

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

Section 1. Introduction

1. My name is GRO-B and my date of birth is GRO-B GRO-B 1981. My address is known to the Inquiry. I am employed as an GRO-B I'm married with one child. My wife is called GRO-B GRO-B and my daughter is called GRO-B and she's currently GRO-B I intend to speak about my infection of Hepatitis C through blood products I was treated with in relation to my Haemophilia. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my family and our lives together.

Section 2. How Infected

2. I suffer from haemophilia A and require factor VIII. I've always been on factor VIII treatment.

3. I was 10 months old when I was diagnosed with haemophilia in 1982. This is severe. I require treatment every other day. I believe first all I was treated by the Sick Children's Hospital in Edinburgh as we lived in GRO-B There may have been one visit to Nine Wells hospital in Dundee. I was treated at Yorkhill hospital after that until I was 16 and then at Glasgow Royal infirmary.

4. At Glasgow Royal infirmary my consultant was always a Professor Low and in my time at Yorkhill it was GRO-D. I believe there was a senior registrar called Dr P Galea and this was at a Dr Shanks unit in Edinburgh.

5. I moved back Glasgow in 1995 or 1996 after that all of my treatments were in Glasgow.

6. I do not know when I would have been infected. I believe I would have been infected by my early injections in Edinburgh and that was just with speaking with other people who were infected. I believe that the first mention of my infection was in 1991. This is from a GP letter from 2008. There are comments in my medical notes and there was comment of a risk of it in 1986. This letter was from a Dr Pettigrew at Yorkhill hospital.

7. I have no record of my parents being informed and the dates seem quite sketchy. From memory I believe I was told between 1992 and 1994. There was nothing put in writing. I believe my parents were

summoned to Yorkhill hospital and it was GRO-D who told them. I was not with them when they were told. I believe there may have been some extra testing in 1988.

8. I remember my parents told me the same day that they were informed. They were visibly upset and did not have a lot of detail. I think their emotions maybe got the better of them at that point. I would have been between 12 and 14 years old so I did not take it very seriously at the time. I do not remember speaking to a doctor about this. It seemed as if it wasn't my problem. I believe it was explained as a bit of a brush off to my parents. They used the term antibody in a positive sense to imply that it was not active illness. I think they tried to make it seem less severe than it was. I do not believe adequate information was given as I do not believe that even any leaflets were given. I think the only contact that time was the consultant haematologist who was Dr GRO-D I believe they should have let me know the risks earlier or at least let my parents know the risks earlier, since it was referenced in 1991, the risk of hepatitis C. There was also mention of a risk in a letter from 1988.

9. There was no mention of any treatment or how to manage the infection I believe. There was no advice given about cross contamination or anything like that. Even when I was older, I was told the risk was negligible.

Section 3. Other Infections

10. I was infected solely with hepatitis C

Section 4. Consent

11. I do have a suspicion that I was tested without consent. The GP letters I have in my medical notes referenced testing. I believe this would have been in 1988. The letter in 1991 says about hepatitis C,

they must have tested me without consent. There was no mention from my parents about consenting to any testing. The letter from 1988 says that I was tested in 1988 and that was from a Dr Pettigrew to my GP GRO-B They said they took blood today and it mentions testing this. They may have known as far back as 1988 that I did have hepatitis C.

12. I believe I had my hospital records once before and for I did not look at them. My wife thought that what was redacted was blacked out. This was around 10 years ago and I believe previous solicitors were involved. I can't remember why they were involved but they did turn down taking on my case. I believe my parents or someone else encouraged me to pursue a legal claim and I went along with it.

Section 5. Impact

13. Prior to my diagnosis I did not suffer from any symptoms from having hepatitis C. I had no flulike symptoms. I believe there was no impact up until the age of 22. I did not feel affected so I even put treatment to the back of my mind for a long time. There reason I did that was because I believed it was benign as the doctors had minimised the condition when they spoke about it to my parents and to me over the years.

14. In later years and now, things are very different. I have cirrhosis of the liver and I have a long period of not attending the liver clinic. Dr GRO-D at Glasgow Royal infirmary, GRO-D, said I would not be considered for treatment as I was a non-responder at one point. There is no indication that I am currently in a bad way but they were quite critical of me. There were questions about my treatment in 1996 doubting me and if I would had have really persevered with it. I got fed up will all the questions and stopped going.

15. In 2007, I went back and it was only really then I began to understand the impact.

16. The tough times started in 2007. Prior to that stage I felt asymptomatic. I believe it was in February of that year that I started to notice symptoms. I began to understand that there was no such thing as antibody-positive as they had described. I was diagnosed with cirrhosis in October of 2011 I believe. I went to the clinic and had no biopsies done due to my haemophilia. I believe they did a bio-scan and they found that I had active viral hepatitis. I had a reading of 36.3.

17. I have a letter from 14th October 2011 in my medical records which states that the value of liver stiffness was compatible with advanced fibrosis and previously established cirrhosis.

18. One of the biggest impacts has been on my wife. I was on trial for ribavirin with Sofosbuvir and my wife got pregnant while was on this. The advice I was given by the doctors treating me was that my wife should have the baby terminated due to significant risk of limb deformity due to the medication I was on. They said it could be limb deformity or even worse. I believe this was from the animal trials which showed that there was a risk to the number of animals that were on it. This was in 2014. I believe that this trial was stopped in the end due to the effect it had on children. This was an exceptionally emotional and stressful time. This was the first time that my condition had truly affected someone else. I reported to my GP with low mood anxiety. It was bad at other times and I managed but my number was concern was the security of my wife and child.

19. We live in a flat and we cannot get mortgage as I cannot get life insurance. This is part of the worries I brought up to my GP. My GP prescribed anything and I was offered counselling but I did not take it. I feel that I am generally managing myself.

20. As a younger man I worried about my interaction with females. I believe this did have a social impacts and I was lucky to meet someone that it didn't make a difference with. I sometimes have to have time of work because of my bleeds. I always worry about what people think but my employer has been good about that too.

21. Even when I go to the barber I have to explain that my condition, in case they cut me by accident or anything that.

22. In terms of the treatments I've received over the years, I would say that I had interferon in 1996. This was initially at Yorkhill. I believe I was on this for 48 weeks and was non-responsive. They didn't strictly say it was the genotype but it did not seem to work. I was off school for nearly a year so this did have a major impact on my education. I was, just again, in 2014 with another trial which was ribavirin with Sofosbuvir and interferon. This is a three prong treatment. I later had Sofosbuvir again in 2015 I believe and this was my last treatment and this was successful. I was found to be clear in June of 2015.

23. When I had the interferon treatment in 1996 I was very unwell and suffered from flulike symptoms. I had rashes and was itching a lot. I had a loss of appetite and missed a lot of school that year. This was the year or year before my standard grade so it did badly affect my education. I did suffer from brain fog and it was a lot of having a bad flu. People could be talking to you and you just sort of glaze over.

24. When I had my treatment in 2011, this was a week at home but I did have the same symptoms as I did in 1996. As an adult it was easier to deal with. As a child, peers were moving on and I struggled with the things I was missing out on. I think the main impact was my wife having to look after me. We had a one year old your baby at that time and I had to miss a lot of work. I did last the 48 weeks on that treatment.

25. My two later treatments that did it eventually were much shorter courses. With them I suffered much more of a low mood.

26. The physical symptoms were much like before but generally the low mood was relatively new. I recall not wanting to continue the treatment but I did persevere.

27. The biggest complication has been the fact that we had to terminate that pregnancy.

28. The main obstacle I had to receiving treatment was I had a long period under Dr GRO-D where he said that the policy was not to treat people who were non-responsive with other treatments such as ones with interferon. I did not have any treatment between 1996 and 2011 because of it. They should have made it available and I would have taken treatment if I was given the option.

29. The only thing that ended up working was with Sofosbuvir. There was no information given about other possible treatment.

30. I do not think there was any impact on any other medical treatment I ever required and I did disclose this to my dentist but this did not have any impact on this.

31. In terms of family life, I am worried have my daughter sees me. Between the ages of 1 and 4 she would have seen the effect of treatment on me. I am worried about the long-lasting impact of this. It would not have been good for her to see me in bed as much as I was during that time. She is quite a sensitive little girl and notices things. I do have recurrent and required surgery on my knee to have a replacement. This is a degenerative condition.

32. After the termination that my wife had, we had to take a decision from a moral standpoint and we decided not to have more children. We did

not plan to stop at one child. My wife was informed at the time of her termination that other pregnancies could be complicated by the termination that she had. My physical health also plays into the fact we will not be having more children.

33. I try to live life the way I am supposed to. I do enjoy a drink but I do not drink very much. I live as far as I can with advice have been given. I do not know if my condition will change for worse. There has been no mention of my liver being damaged enough for a transplant yet. They said I have significant cirrhosis but my function tests are fine.

34. It took a while for us to recover from that termination that my wife had to have. I believe I have recovered but my wife maybe not. My wife suffers from clinical depression since I've known her so this has probably impacted how much that she has been impacted. She did want more children, she's had to accept that I do not feel that physically capable of looking after more children.

35. In terms of my social life, I'd say it's had a massive impact. My friends go to watch football in the pub or go for a midweek drink but I feel like I attract attention by the fact that sometimes I do not have an alcoholic drink. I will get jibes from my friends for not drinking. There was a period where I would go for 2 pints and then switched to tea and my friends would make jokes. I've had the same group of friends for a long time and they know about my condition. Those that are less knowledgeable do not and will occasionally make worse jibes. I believe haemophilia is not well understood and not everyone really knows about it.

36. In terms of my social life, my wife, I would say it has had an effect on that although not in the last few years. I think it was mostly affected during the long periods of treatment. I had so many sets of treatment that there were a number of times that our social life as a couple was affected. After 3 non-successful treatments there was a period of

disappointment for both of us. There was a sense of euphoria after my final treatment.

37. There were times in the past we would have done things like go on holidays. We went on holiday recently and it was £600 for medical cover while we were in Florida. I note recently that the cost has gone up. It used to be £50 or £60. I think we'll now be putting of going to Florida again because of the cost of my medical insurance. We are more likely now to go to Europe. I'm worried about any bumps or a fall while I'm on holiday. I still have to take my treatment on alternate days.

38. In terms of my education, at school I did do Highers but I did not do well. I felt at that time I was more than capable but I had missed a whole year of standard grades, my heart really wasn't in it. I felt that I had fell behind. I left school and did an apprenticeship.

39. I believe this was a huge impact. My younger brother GRO-B works in GRO-B I felt like I was even playing catch up with him after my time off as well as with all my fellow pupils. Bizarrely, my standard grades were not too bad. I got seven grade 2s.

40. In terms of my work, in 2011,2014, and 2015, I had sustained period of sickness due to the treatment I was having. I do often have long periods off of work due to my haemophilia anyway. I don't think it really affected my work too much as my employer is very good with me. It has affected my outlook on going elsewhere as I do not know if any other company would be willing to put up with my haemophilia. I have been offered jobs before and turned them down. There is a great risk of going somewhere and then an employer being far less supportive.

41. My haemophilia has had no impact on my salary even with the times off. I believe that my diagnosis has affected my confidence and my ability to progress my career. I have worked for a consultant who earns four or five times what I earn and I feel that I'm capable of doing that job. I'm worried about not getting a job when I apply for it. I was off for 8 months between March of 2017 and December. I had my knee replaced and this did require time off work. I'm intermittently off maybe four or five times a year with a bleed. I can work from home so that helps. I will eventually need my other joint replaced and I am currently under consideration for an ankle fusion. I have steroid injections to manage the pain. I have issues with my ankles, knees and elbows.

42. In terms my relationship, I do believe it may have had an effect but I am unsure.

43. I worry about how people see me. The stigma does not really affect me overtly but I have never been a victim of discrimination so I probably internalise a lot.

44. There was a big connection between hepatitis C and AIDS when I was a child. The way the hospital put it to me was that it was like a lottery that I had hepatitis C and not HIV. They downplayed it and played off as the lesser of two evils. It feels that more people know about haemophilia than hepatitis and I worry about people linking the two.

Section 6. Treatment/Care/Support

45. In terms of any counselling offered I would say there were always posters in waiting rooms. It was only offered once when I went to the doctor with low moods. One time was during treatment and the other was quite recently when I had a low mood. I had low mood in 2014 and in September of this year. I had some bleeds and needed some

space. I do not know if I would have benefited from treatment, in terms of support or counselling. I dealt with it myself but I can't say I wouldn't have considered support or any sort of counselling if it had been offered.

Section 7. Financial Assistance

46. I did receive money through the Skipton fund. I think initially, I got a lump sum around about the time I started going out my wife. I am unsure of what that lump sum was. I think I may have got £11,000 over 12 months. It was only in 2011 when they found I had cirrhosis that they moved me on to stage 2 and I believe I received a further lump sum of £50,000. Now through SIBBS I am receiving £18,000 per year over the course of 12 monthly payments.

47. I believe it was a consultant called Dr Alvey who made me aware of Skipton. He was a doctor at Glasgow Royal infirmary. He was very helpful and I found the process quite easy. I believe I was moved to stage 2 at the advice of a Doctor Euan Forrest who was a gastroenterologist. I do not recall there being any difficulties in my accessing these funds. I was able to see my medical records and I had no difficulties. This has somewhat helped in saving for a mortgage. No preconditions were imposed on us.

48. I did not receive anything through the Caxton fund. This seemed to be means tested and both my wife and I have been working so this did not apply to us.

49. In terms of the new SIBSS payments, I believe this was an easy form generally. This form said something about advising Skipton to transfer details over to this new fund. I do not recall there being any difficulties in applying and it felt like more of a changeover. This now means that I get £27,000 over the course of the year. The money is great but it is sort of drip fed and it makes it difficult to make long-term plans

financially. It seems almost just like disposable income and we'd much prefer to have a house. This is difficult with the way it is drip fed to us.

Section 8. Other Issues

50. In terms of what I thought about Penrose, I would say I did not think a lot about it. I was not entirely engaged with it as it was going on. I did not go to the hearing I did read the report. Someone came and took a statement but it was not as detailed as the one I'm giving now. The problem is accountability and how I am going to manage the rest of my life. I am fully understanding of the fact that I may not live as long as other people now. It feels like a race against time and I am hyperaware of my own mortality.

51. I wish for my statement to be made anonymously.

Statement of Truth

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

Signed GRO-B

Dated 11·2·19.