Witness Name: GRO-B
Statement No: WITN2172001
Exhibits: None
Dated: 08 February 2019

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 5 November 2018.

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

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1959. I am married to my wife GRO-B and we have a daughter, GRO-B I currently work GRO-B.

Section 2. How Infected

2. I suffer from haemophilia A and this is severe in nature. I take a prophylactic treatment three times per week.

3. I'm currently on the recombinant factor 8 and I have previously been on fresh frozen plasma cryoprecipitate, factor 8 and recombinant. There may have been others in between but I am unsure of their product names, if received.

4. I am currently treated at Glasgow Royal Infirmary. Initially I was dealt with by Yorkhill between 1960 and 1964 or 1965. This was the old Yorkhill. That Yorkhill was demolished and at that stage I was transferred to Oakbank between 1966 and 1969. I was then dealt with by the new Yorkhill between 1970 and 1976. I remember being there on my 15th birthday and the comments on me moving up to be treated as an adult. I was thereafter treated at the Glasgow Royal infirmary.

5. I do not know who treated me at the old Yorkhill. I do not remember. From the 70s onwards I was dealt with by a Professor Hutchison, Professor Willoughby and a Dr William B Doig. These are the people who were responsible for haematology at that time. I have also been dealt with by a Professor Gordon Lowe know who is responsible for the unit at Glasgow Royal Infirmary. Another professor, Professor Tait came in the last 20 years.

6. In terms of treatment for my haemophilia from the age of four or five I was admitted maybe three times per year. This would be bleeds and bumps and in some cases I just needed clotting factor. I was only really treated when something happened such a bump or a scrape or a bleed.

7. In terms of when I was told I had hepatitis C I would say this is a bit of a grey area. I believe it would have been around 1993. My daughter was born in 1993. I believe my wife was also tested around this time. I believe it could have been earlier than 1993. It was Professor Lowe who told me about my having hepatitis C. He said not to worry about it and that we would be talking about 40 or 50 years down the line when it would be something we would need to discuss.

8. When I discussed with that same doctor about the use of blood from America he said not to worry. He said it was all good stuff. They said that you didn't need to take it if you didn't want to but I knew there was a shortage at the processing facilities here. I felt the doctor minimised everything. I feel that inadequate information was given. I feel that I was given what they wanted me to hear. I feel that they knew more than they were letting on at that time. When I have had treatment I know there have been discussions about the centre directors going to conferences in the 50s when there was talk of pooled blood and the increasing risk of infection with what would then have been non-A/non-B hepatitis. I think when they started using product from America the information given. was quite shabby. I think we should have been told that there was a high risk given that they knew there was at least some element of risk.

9. In the early days I was not on prophylactic treatment and I was in and out all the time having treatment. I would be in every couple of weeks for a bleed or for a physio. There were lots of opportunities to speak to doctors but I feel they minimised it all.

10. I also remember them taking blood and I remember them testing for hepatitis C. They took a sample of my skin like an apple core. It was not long after that I got told. I asked at the time if this device that was like an apple core was related to testing for hepatitis and they said it was to do with studies they were doing at that time.

11. In terms of information given about cross infection I would say that it was very patchy. There was no support worker or anything there to tell us more about cross infection. They said it can be passed on and that you need to be careful in the house. They mentioned things like sharing toothbrushes and being careful about any blood spills. They said to be careful as much as you can at home and at work. At work they said not to share cups. This made me quite paranoid and I didn't want to tell people as I did not fully understand how this could be passed on. It was also at this time that we were going to try and have our first child. I was in 1991 and 1992 that we had been trying. I do remember my wife got tested and this came back negative.

12. I feel that generally information was just lacking. All they really said was to just make sure to clean up blood spills and that's my main take away from it. I recall I had a lot of nose bleeds around that time and it made me worry about this and any contact my wife or child could have with this.

Section 3. Other Infections

13. I contracted hepatitis C.

Section 4. Consent

14. I found it very coincidental that around the time they took the lump in my arm they found out about my hepatitis C. They even a couple times mentioned research around this time. I do not remember signing any sort of consent form about this. I think I only signed forms in early 2000s for genetic research. I feel that there was definitely research going on but I was not privy to it and my blood samples may have been used for this. My blood is taken very regularly so I didn't

question what it was for. It is the sort of thing that becomes routine. You just sort of presume the doctors and nurses know what they are doing so you don't question it at the time.

Section 5. Impact

15. I had flu-like symptoms prior to my diagnosis. I was also susceptible to getting throat infections and I don't know if that was related. During the 80s GRO-B so I was working and travelling a lot so there were options to sleep sort of through the day sometimes, I could sleep until maybe even through the afternoon. I could sleep as much as I wanted. I do not recall having any symptoms of what has been described to me as brain fog.

16. In the 1990s I noticed that my confidence wasn't as great. It was around that time that information was coming out about hepatitis C and it was also in the 1990s when I believe that some of the symptoms that may now have been hepatitis C started to affect my work. I noticed I would be drifting in and out of conversation. My wife noticed that I would drift off in conversation and I was just not focused. It wasn't like me. Prior to when this started to affect me, I thought that I was quite a good listener.

17. I do not think that I had any flu-like symptoms until I had my treatment.

18. I have had issues with my liver. I went to the doctor to report that I had a pain in my right hand side about the liver are in the mid-90s. I was sent to a Dr Morris at the Glasgow Royal Infirmary who did a fibre scan. He did tests and didn't find anything initially but then when I was taken back he said the results quite high and were higher than normal.

19. I had my first batch of interferon in 1994/1995. During the treatment I suffered from flu-like symptoms and felt sick and dizzy. I was on this treatment for a year. This involved injections at home. I had already started practising using a needle when I was administering my factor 8 treatment with recombinant and we used an orange to practice as an orange offers the same resistance as skin would. It was just shy of a year when they realised that this did not work. It was two six-month courses. The said there was nothing else available. I believe it was maybe around the year 2000 when they came up with different alternatives. I had symptoms from treatment for at least 12 months after. My eyesight also been affected. I was more susceptible at this time to colds and flus. Thankfully I did not have any thyroid issues.

20. My second round of treatment was something called Talapovir and they said it would be forty-eight weeks and I went on it for eight weeks. I remember coming out in a rash and it got worse and worse. I saw the dermatologist and they said this was a systemic issue. I had a discussion with Dr Morris and he decided to take me off it as it would be dangerous to continue treatment. I was off it for four weeks and then they said I would be going on to another one once my skin had cleared up of the rash on 70% of the my body. At this time they did a blood test and they said that I had already cleared myself of hepatitis C through the treatment I had had. The rash was like ants under my skin. The rash was everywhere. They had to give me cream to stop me scratching my rash. Since I stopped taking the medication I cleared the rash within a month or two. I had no other symptoms that point. I got a letter about the risk of vCJD and I decided I did not want to know, this would have been in 2002.

21. I believe I have always been lucky having access to treatments and I think there was a possible delay but there was no sizeable delay.

22. With hepatitis C after the first treatment where I was non-responsive, there were new drugs coming up but there was nothing available at Glasgow Royal infirmary for me. I think they were treating younger people first and they said they would get to us if there was more funding. They seemed to be in no rush to get people treated.

23. I was treated alongside drug addicts at the liver clinic. I would say that 90% of patients there were alcoholics and drug addicts. It was a very difficult clinic to attend, but the staff are great. The staff treated everyone the same, I was scared in case someone from my work saw me there.

24. In terms of other treatments made available I would say that when they became public there was a lot of talk of HIV and hepatitis C and there was a mention of a lot of treatments in the USA although I felt that more of these treatments were for HIV. I think this to some extent trivialised hepatitis C as it was felt to be the lesser of two evils. No one ever seemed concerned from the doctors' side about hepatitis C. They only seemed to start being concerned if you started showing liver symptoms but this was generally too late to seem concerned, I believe.

25. In terms of any barriers to treatment I think there were none in terms my dental treatment. Any time I go to my GP it is mentioned. I remember in Glasgow Royal infirmary I was going in for an X-ray and they said they were going to take blood and I said to the girl about my hepatitis C and then she heard this, she left and someone else came in to take blood. With my dental treatment, I recall saying about my nosebleeds I was sent to an ENT clinic. I raised with them that I was haemophiliac with hepatitis C I felt that they did make a thing of and it was noticeable that I wasn't treated quite the same as others.

26. In terms my family life I would say that the first impact was the whole stress of finding out. I kept thinking that this would have an impact on my wife and any future family we had. I needed to consciously think about infecting others and I was paranoid about this. I was also worried about people finding out. I felt that people couldn't really make the distinction between hepatitis C and HIV and they would have made assumptions. I decided not to tell anyone other than my wife. I did not even tell friends of thirty or forty years about it.

27. My wife was very early on in her pregnancy with GRO-B when I found out about my having hepatitis C. I asked about the chances of my wife being infected and they said if my wife was okay then my daughter probably wouldn't have it. I believe my wife was tested 1994. After GRO-B we decided not to have any more children. We weren't even sure if we could have unprotected sex. I believe we would have had at least one more child if it hadn't been for my hepatitis C. My wife is from a big family. At one stage we did consider adoption but we decided not to because we were worried about me having future health issues and my wife being left to deal with any other children we had.

28. My condition has also had an impact on my social life. I was always out about before and had lots of friends. A few of them knew I was a haemophiliac and some even asked if I had AIDS. I started being a bit of an introvert over time after being diagnosed. I feel that I became withdrawn and went out less. My confidence hit rock bottom. I used to go out with guys from work and people would make jokes about things that I hadn't even told them I had just because of what was in the media. They would make jokes about people with HIV or hepatitis and I felt like if only they knew the issues I was having. I feel like if they knew, they wouldn't have made the commented comments they did.

29. My wife got scared of what was going to happen with my condition, too. I was worried about my haemophilia or hepatitis C coming up in conversations with people who did not know about it. I was a GRO-B GRO-B and people finding out. I treated my condition on a need-to-know basis with people.

30. My daughter was very young when I was diagnosed with hepatitis C. We only really went into it with her GRO-B GRO-B she was 17. She knew I was a haemophiliac before and she could understand that. I do believe that she was about 16 when we started to get a lot of letters about things like compensation so questions did come up. We waited until she was an age that she could understand it.

31. With the impact on my work I would say that my ability to concentrate was badly affected. My concentration was low and I was worried about people finding out as well about my condition. There was not a lot known about how it could be caught so I worried about things like people accidentally using my cup and things like that. I worried about people's ignorance about the condition. I went through a period of after being there for three or four years where there were promotions that I just didn't go for it. I lost a promotion in 1994 or 1995 as I did not go for it. I had to go to my doctor's because I had shortness of breath and suffered from stress and anxiety. A lot of people asked why I wasn't going for it, but I did not tell any of them why at that time. I did eventually get promoted in 1998 and then I had two other opportunities to get myself through, but stress affected me. I was really doing a lot of higher position jobs in all but title. I was worried about having the added responsibility with my symptoms of hepatitis C. I believe that not going through these promotions has cost me what must be now around £100,000. I have lost out on at least £5000 per

year. And that is based only on these promotions. A girl who sits near me joined at the same time as me and she has had four promotions since then and I believe she would be on around £60,000 per year. I feel that it could have been me getting the same promotions had I not had my symptoms of hepatitis C and my treatment.

32. I tried to work through the time I was on interferon and I used annual leave to try and get through this. I do feel that my condition stifled my ability to go further in my career and it prevented me from going along the career path I wanted. My brain fog was also something that came up then with people telling me things at work and I would have to write them down to remember them. I still get the brain fog now.

33. In the last two years I have been getting near to retirement age and I have been struggling for the last five years. GRO-B GRO-B so now I work three days per week.

34. I did not declare my hepatitis C on my mortgage application. I do now have life insurance and pay a premium for this and that is £30 per month plus my wife's is £10 per month.

35. I would say with travel insurance, it is normally the best part of £80 more expensive based on our annual policy. I used to get free travel insurance through my account with GRO-B they said that I was no longer covered when I disclosed about my condition. I do not declare my hepatitis on things now as my hepatitis C is undetectable during tests.

36. With my liver I do have liver scarring and a level fibrosis. They said that the level of one of my fibre strands was at 11. At no point have we discussed a transplant and because when I get my bloods done now directly they say that it's at a normal level. I do get occasional pain my liver maybe every second day but this has been put down to liver stiffness.

37. I have started getting kidney and gall stones. Medically they say that this is a separate issue, but I know that this can be caused by a liver not functioning properly and that is what can cause these sorts of issues.

Section 6. Treatment/Care/Support

38. It is only latterly that I was offered support in around the year 2000. They said that there were counsellors that I could go to but this was well after that the damage had been done. I do not believe this would have done much good to me. I believe I would have benefited from counselling much earlier and I would have been more aware of what was to come. It would have been better to be more aware of what can come up, especially with the symptoms of treatment.

39. I definitely suffered from depression at one stage. I went to my GP over my anxiety and depression and he offered medication to help me sleep. I was reluctant to go down a psychiatric route.

Section 7. Financial Assistance

40. With the Skipton fund I got my stage one payment in 2004 and this was £20,000. When Caxton formed my wife had just started reduced hours at work to help around the house as I was not able to help. We did get into some debt and we did get financial assistance from Caxton to clear this debt. All we had to do is tell them my financial position when they paid off two of our credit cards and they also at one stage paid for a new roof. At one point we were going to apply for a new boiler but there was some sort of green energy scheme and they were not able to get this through in the end. I found the funding I

went for to be an easy process. I remember having to get free quotes for the likes of the work to the roof and that was passed to them and they picked one of the quotes.

41. I did receive £30,000 from the Scottish government in the last couple of years prior to the Scottish Infected Blood Support Scheme. I believe the government decided that those who hadn't received £30,000 already would get it. Again this was an easy process.

42. I haven't received money from the Scottish Infected Blood Support Scheme. I marked myself as severe and now receive £1,575 a month. This does at least make up for the shortfall in my pension. This was an easy process to sort out the forms of this. I'm involved in the Scottish Infected Blood Forum and there has been a lot of fight to get where we are now. I have never been a campaigner but I feel that I have done my bit.

43. I think that what's on offer now is adequate but was not before and I'm worried about them continuing to maintain this current structure. I also had issues where I because, my feeling the cold more I had to have higher heating bills than I would have normally.

Section 8. Other Issues

44. I was not involved with the Penrose Inquiry, but I did follow it. I went to a couple of meetings but I never gave a statement and nor was I a core participant. I was involved in an American litigation where American lawyers decided to sue drug companies. I believe this was against Baxter and other companies but this was a whitewash. The firm who represented me in America were Lieff, Carbraser, Heiman and Bernstein LLP. In the end I got £5,000 from this, it was an

absolute joke and I think they played up the figures to us in order to get me on board.

45. I would like my statement to be made anonymous.

Statement of Truth

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

Signed GRO-B

Dated 9\3\2019