ANONYMOUS

Witness Name: GRO-B
Statement No: WITN0203001
Exhibits: **WITN0203002-5**

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 14th February 2019.

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

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1946. I live on the GRO-B, my full address is known to the Inquiry. I am retired and I live with my wife GRO-B of 49 years who has assisted me with this statement. I have two daughters and one son, GRO-B, GRO-B and GRO-B who were born in 1971, 1976 and 1982 respectively.

2. I intend to speak about my infection with the Hepatitis C virus (HCV), which I contracted in 1978 as a result of being given cryoprecipitate before and after dental surgery.

3. In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment I received and the impact it had on my life and my family.

4. I am a positive person and I try to apply that mental attitude to all things in my life. Prior to the infection my wife and I were social people who enjoyed spending time with friends and family regularly.

5. I am not legally represented, I am happy for the Inquiry team investigators to assist me with my statement.

6. For personal reasons I wish for my identity and the identity of my family to remain anonymous.

Section 2. How Infected

7. I grew up in GRO-B in GRO-B in GRO-B and I lived a very normal life. In 1953, I had my tonsils removed and during the surgery a vein at the back of my throat was cut accidentally. From this surgery I found out that I was a haemophiliac. As a result of the bleeding the Doctors and my family thought I was going to die.

8. I was a given a blood transfusion after this operation directly from the doctor's arm into mine using two tubes and a syringe in the middle. This was the only way to save my life. I had not been given any clotting agent, as there wasn't the option at that time to have it.

9. I recovered well from the operation and the transfusion and I carried on living a normal life playing football and going through everyday life with

no problems. I occasionally had some mild bruising but I never had any heavy bleeds. I could bandage up wounds and they would eventually clot, I never needed clotting agents.

10. When I was younger, my Factor VIII levels were 3% making me a mild haemophiliac and over time they improved, by the time I was an adult my levels had increased to 8%.

11. I had worked in catering in the kitchens of a range of luxury hotels in GRO-B and attended a school teaching you about each department of a hotel. I left GRO-B at 19 and I became a waiter in a local hotel over here. That was where I met my wife GRO-B we have been together ever since enjoying travel and raising a family together. We were married on 31st January 1970. I continued to work in the hotel business and GRO-B was a housewife.

12. In 1971, we had our first daughter GRO-B and I became a hotel manager. We moved around quite a bit at that time, travelling and working in various places across England but we eventually returned to the GRO-B in 1975, and in 1976 we had our second daughter GRO-B

13. In October 1978, I had a problem with my teeth and I went to the dentist to resolve it. I told my dentist that I was a haemophiliac and he recommended that I have the work done at the local hospital so that they could give me plasma if I needed it.

14. I went to GRO-D to have the operation and everything seemed fine. I had been given cryoprecipitate before and after the surgery as a precaution as I would need stitches; I have my medical record, which supports this. **WITN0203002 refers.**

15. I actually told the hospital staff that I didn't want or need the cryoprecipitate but they were adamant. I stayed the night and went home the next morning and had no experience of any problems, our lives carried on as they had always done.

16. We moved to GRO-B in 1980 and started a GRO-B business in GRO-B GRO-B In the same year I was treated for haemorrhoids at GRO-B GRO-B, GRO-B and I was given heat-treated blood products as part of the operation. Afterwards the consultant told me that in the future I should always check and make sure that I was being given heat-treated products.

17. In June 1986, it was discovered that some of the levels in my liver weren't right and so they did some tests on my liver. The tests came back negative for HIV but positive for non A non B hepatitis. They didn't have a test for HCV then. I didn't know what Non A Non B hepatitis was.

18. The doctors at GRO-B told me, that I should go to see a hepatologist when I go back to England, as they didn't know how to treat it here and that the doctors in England would know better. GRO-B: W was also tested for HIV and she was negative.

19. We came back to England in 1987 and I received Factor VIII for the first time in 1992 when I had some kidney stones removed. As I had been told that I had non-A non-B hepatitis in GRO-B I could have only been infected from the cryoprecipitate infusion.

20. It wasn't until 1999 when I went to the Haemophilia Centre at Royal Liverpool University Hospital for general treatment that my haemophilia consultant, Dr GRO-B tested me for HCV. She asked me how I wanted to receive the results, phone or letter? I said just tell me at my next appointment. It was then when I was told that I had HCV. I didn't have any of the HCV symptoms and never had any. I felt nothing that would

make me think that I had HCV. My general health at that time had been good.

21. Within a year of my HCV diagnosis, I had to have a liver biopsy. I was under Dr GRO-B and Professor GRO-B. It was Professor GRO-B who showed me the degree of damage that had been done to my liver from the infection and told me that I had a fatty liver. He told me to cut out alcohol to give my liver a chance of recovering, I told him that I never really drank alcohol anyway so that would not be a problem. My wife and I have always kept a healthy diet and still do.

22. Dr GRO-B told me that I had a gallstone the size of a pigeon egg; she wanted to remove it as soon as possible to prevent any further problems. During the operation the surgeon removed the stone and performed the biopsy at the same time.

23. Following my liver biopsy, I was referred to see a consultant on the GRO-B, Dr GRO-B (now deceased) about the treatment for my HCV. He told me that it was not worth having treatment for the HCV as it was very expensive and there was a chance that it wouldn't work. I reported this to Dr GRO-B who told me that this was not anything to worry about and I would most certainly receive the treatment.

24. I began treatment in 2000, which lasted 56 weeks and involved me taking Ribavarin tablets twice a day and injecting myself in the stomach with Interferon every other day. Throughout the treatment I was worried that it wouldn't work or that it would appear to work and then it would come back as I knew the treatment didn't kill the virus completely.

25. I felt quite low throughout the treatment but I mostly tried to close it out and always kept looking forward and kept my mind positive. That was the best way for me to cope with what was happening.

26. During the treatment I used to have to lie down for most of the day as I experienced chronic fatigue. I also had a lot of nausea and headaches

throughout. I was very pale during the treatment as my haemoglobin levels were below ten.

27. The fatigue lasted even after I had finished the treatment. I remember going on holiday to Venice and I spent the entire trip slumped over my wife's shoulder as we walked around.

28. I was told in 2001 that the HCV was undetectable and so the HCV is now controlled but not gone, my understanding is that this treatment can't eradicate it completely.

29. I go to the Royal Liverpool University Hospital every 12 weeks for treatment for my haemophilia and they check my liver, blood and kidney functions each time. My liver was scanned three years ago and it shows scarring, I have been told it is in the same state as an alcoholic's liver.

30. In February 2009, ten years after my HCV diagnosis, I was sent a letter explaining that I had received a batch of blood products, which had used products from a donor who was then discovered to have vCJD, **WITN0203003 refers**.

31. I am glad I was told about the possibility of developing the infection as I want to know what may happen to me in the future, but I am still worried about the future.

32. Since I got the letter, I have talked to doctors about how they can know about vCJD donors and they tell me they can't know when they donate which is very worrying, even more so is that they can't kill the prion which causes vCJD as it is not alive. This weighs on my mind heavily and I'm very worried that I may develop it.

33. vCJD is the biggest worry I have as I don't know when or if I will ever develop it, I don't know the incubation period and the fear of developing it lives constantly inside of me. It is always there in the back of my mind that the vCJD may become my life.

Section 3. Other Infections

34. I have not received any infection other than HCV as a result of being given infected cryoprecipitate, however as previously mentioned I did receive blood products from a batch from someone with vCJD. I do not know if I have vCJD as a result of this but I am aware that is possible.

35. I have experienced gallstones and kidney stones since having been infected with HCV.

Section 4. Consent

36. I consented to all the tests, which were performed on me as did my wife GRO-B I have never been tested or treated without having given consent.

Section 5. Impact

37. In 2010, I developed an inhibitor, which is an antibody, which fights any foreign bodies such as Factor VIII. If I had a low quantity of Factor VIII then my body would accept it but if it was a larger dose than my body could reject it.

38. In 2010, I was doing some tiling and I ended up with a big muscle bleed in my thigh. I went to the GRO-D, they apparently tested my Factor levels and I was told that I was 100% when I was actually very low. They lied about this.

39. The following day I was taken to the Royal Infirmary in Liverpool by air ambulance where I had to have 20,000 units a day at eight-hour intervals but my body rejected it. This is the cause of the Inhibiter, the amount I was forced to take in such a short period.

40. For the last eight years I have had a PICC line fitted feeding into my heart which is constantly there as my veins have collapsed. I had to self-inject the Factor VIII into the PICC line for three months and then GRO-B had to be trained as a carer at Royal Liverpool University Hospital by the specialist haemophilia nurses.

41. Sometimes the PICC line becomes blocked and it has to be flushed out, GRO-B: W now has to be quite aggressive to get the Factor VIII in.

42. I have to be very careful with my PICC line as it is very susceptible to septicaemia and so everything has to be sterilised and there is a lot of care involved to maintain it. Unless they come up with a new treatment I will have to have it and live this way for the rest of my life.

43. All tests say that the inhibitor is undetectable but it is clear that it is there and this adds to my worries about my HCV not really being gone as that is classed as undetectable as well.

44. As we live in GRO-B I have been always very concerned about the stigma associated with HCV. I have been very wary since my diagnosis and I have felt unable to tell anyone about my infection as people talk and word spreads quickly where we live.

45. We used to socialise regularly with people and group of friends we would see often but we stopped that after my diagnosis and isolated ourselves out of fear of someone finding out about my infection. I also didn't want to go to social events as it often involved drinking alcohol and I didn't want to have to explain why I wasn't drinking to people. At the beginning I was very concerned, I didn't want to be looked at

differently as I knew there was a lot of misunderstanding and ignorance surrounding HCV. I was worried that people wouldn't want to go near me.

46. We could start seeing people again now that I'm cleared but it has become part of our way of life now after having been this way for twenty years.

47. I am aware of a woman who also had HCV near us and I know that she was told by Dr GRO-B that it would be best for to leave the area due to the level of stigma she would receive. This is a scary story for us to hear.

48. I would really like to have a support network in the community with those who are also infected but the only way to start one would involve me risking the effect of the stigma around HCV, which we cannot afford to take. As we live in a remote place, we are very isolated from events organised by the Haemophilia Society and other organisations as they are too far away and so we cannot access them. I wish that I was able to be part of a community or network like that.

49. My infection with HCV didn't have much effect on my work, I took time off when I was being treated but I went back straight after I had been cleared of the infection. It was other problems such as gallstones; kidney stones and knee replacements which made me eventually give up work and retire.

50. While I was receiving treatment and I was not working we did have to use our live savings to live on which was difficult with three children.

51. The only people who know about my infection with HCV and possible infection with vCJD are my daughters and my son, I have not told anyone else including my brother or other family members.

52. My son and daughters were all very normal when I told them about my infection and were all fairly quiet about it. Luckily, they weren't concerned about the stigma or social effects of the infection. They did not appear concerned about my health as they could see that I was physically fine which kept them calm, they never really thought that something would happen to their Dad.

53. My wife, GRO-B also remained calm during my infection and willingly got herself tested after my diagnosis without much concern or worry. GRO-B has made an appointment to get tested again to ensure that she is still negative and we will let you know the result.

54. When I had two polyps removed from my stomach, the gastroenterologist covered the scope and cut certain parts of it off and threw them away. I didn't feel judged or discriminated by this. The reason this was done related to the potential vCJD infection.

55. I haven't received any difference in care from my dentist. I told my dentist about the HCV and they are happy to treat me regardless. I had to go to Royal Liverpool University Hospital to treat an abscess but that was so that I could have blood products if needed. My infection with HCV has had no impact on my dental treatment.

Section 6. Treatment/Care/Support

56. I have received amazing care from the doctors at the Royal Liverpool University Hospital; the only downside is that I have to travel so far to get there. They have always sent me a copy of my reports as well as to my GP, which has been very helpful for me as my past GP was not very efficient or helpful. I was particularly unimpressed by the attitude she took to my application to the Skipton Fund.

57. I have found in my experience that there is very little communication between medical professionals. For example, on one occasion my PICC line blocked and I required assistance to administer my Factor VIII intravenously, I rang a nurse I knew for advice who worked on the Oncology ward, GRO-D, She told me to come up the following day at lunchtime.

58. Due to the Factor VIII not being prescribed by her department she was only able to insert the butterfly needle and my wife GRO-B had to actually administer the Factor VIII. This was ridiculous; I was 30 hours overdue my Factor VIII and the nurse there said that she couldn't administer my Factor VIII because that hospital hadn't prescribed even though the Haemophilia Centre in Liverpool had prescribed it. The irony is, I collect the Factor VIII from the GRO-D.

59. I was never given any information about how to handle HCV or how to look after it. I wasn't told about any risk of infecting other people and I am still concerned about what happens if I get a small nick at the barbers, particularly after the vCJD warning letter I received.

60. I have never been offered counselling and I would still really like to be part of a support group or network of others like me but that seems very unlikely.

Section 7. Financial Assistance

61. Dr GRO-B got me to register for the Skipton Fund and helped me to send off the necessary proof.

62. I initially gave the Skipton Fund forms and all the documentation to my past GP, Dr GRO-D She put my application under her desk and I

never heard a thing from her. She was very complacent and wouldn't sign anything for the Skipton Fund.

63. Dr GRO-B did help me though and I got a report from the GRO-D's GRO-D which was sufficient for the Skipton Fund.

64. I didn't receive any push back from the Skipton Fund and received an ex gratia payment of £20,000 in 2009, **WITN0203004 refers.**

65. I also received an annual payment of £3,000 and a £500 fuel allowance starting in 2016, **WITN0203005** refers. This has now increased to £1,500 a month since April of this year.

66. As I have to travel often to the Royal Liverpool University Hospital, the NHS pays for my travel there and back so if I do all the travelling on the same day then I don't have to pay anything. Sometimes I stay overnight in a hotel as travel is not always very reliable and the visits to the hospital are long and the NHS will contribute £28 per person a night if we do choose to stay overnight.

67. We are grateful for the payments, which we have been given because we had no financial support during the 41 years my HCV was detectable. I am concerned about GRO-B: W's financial situation if I pass away and this money stops.

Section 8. Other Issues

68. I would like this Inquiry to be able to uncover the people who are responsible for people being given infected blood and I am worried that

they will not be found, and if they are that many of us infected and affected will not live to see that day.

69. I would also like those are responsible to acknowledge what they did and what they knew, not just the Health Secretary at the time but everyone who was involved.

70. In comparison to other disasters and tragedies that have had Inquiries look into what happened, this one is very low profile and I hope that it gains a much wider public profile and is given the greater recognition that it deserves. I hope that this Inquiry can do that.

Statement of Truth

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

Signed GRO-B

Dated 25-7-2019