Witness Name: GRO-B
Statement No.: WITN0368001
Exhibits: **WITN0368002**
Dated: 25th April 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 25th April 2019.

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

Section 1. Introduction

1. My name is GRO-B. I am not legally represented. My date of birth is GRO-B 1969 and my address is known to the Inquiry. I am married to my wife and have been for over 20 years. I have two children and live with my family in Oxfordshire. Professionally, I am a Managing Director for a data & analytics firm.

2. I intend to speak about my Haemophilia and subsequent infection with Hepatitis C (HCV). In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on me, my family and our lives together.

3. My wife and I have decided that this scandal relates to events in the past that we cannot change. We want to move on with our lives and therefore have chosen to provide this statement anonymously.

4. Throughout my statement I have tried to recollect certain dates, times and key trigger events in my life as references to ascertain when certain things happened. This has been difficult due to the passage of time therefore these dates should be viewed as an approximation where stated.

Section 2. How Infected

5. It is my belief that I was infected with HCV as a result of receiving a contaminated batch of Factor VIII Blood product in either the late 70's or sometime in the 80's.

Background

6. I was diagnosed with Haemophilia when I was two weeks old at Mayday Hospital in Croydon (now known as Croydon University Hospital) after my belly button did not completely heal after birth.

7. My haemophilia was a huge shock to my family as I was the first person to be diagnosed with the condition in my family. At the time, my parents were told that I would have to lead a very restricted life and be well protected.

8. My parents took the attitude to raise me normally rather than wrap me in cotton wool or focus on my disability. This meant I rode a bike, played football and was incredibly active as a child. Naturally, the active lifestyle had consequences but I had treatment and it was dealt with afterwards rather than not partaking at all.

9. I remember my mum even managed to convince the headmaster to allow me to play most sports. I'm glad she did otherwise I would have felt like a wasp in a jam jar. Obviously, I wasn't allowed to play certain sports like boxing or rugby. I was also not allowed to play competitively for the school in events – mainly because children from other schools could potentially do a hard tackle without knowing about my haemophilia. I remember being upset that I had to watch rather than being able to play at these events.

10. During my childhood, I loved to play sports. I even managed to convince my mum to allow me to play cricket – despite her being understandably scared and concerned. My mum encouraged me to take up non contact sports like swimming.

11. I don't recall the very early years of my life but remember every time I had a bleed I would be taken to Lewisham hospital – which had a small satellite haemophilia centre. On average, I would say I bled once a week. At the time there was no home treatment so we had to visit a hospital – Lewisham was the closest. It was about a GRO-B trip. 99% of the time I would sit in the waiting room for 30 minutes have an injection and go home again.

12. More often than not, it was my active lifestyle that would cause the bleeds. I do remember two or three times where I had to stay in hospital. These were for more serious issues. For example, once I fell off my bike, hit my head and became concussed.

13. I remember Lewisham being a kind, caring and conscientious centre. The hospital was very relaxed. I was on Cryoprecipitate and they allowed me to take the used bags home so I could play with them. The doctors even threw the used needles into the ceiling as a game. At the time it seemed fun. I believe contaminated blood was not known about or considered a risk back in the late 70's.

14. Up until I was 8/9 years old our holiday destinations were limited and required planning – knowing and being within each reach of a hospital. Everything we did as a family revolved around treatment centres. At the time though, it was not very common for people to really travel abroad.

15. Sometime between 1978-1980 when I was around 10, they brought out home treatment. My mum was trained to administer the injections. She was taught practically and learnt the process by visiting Lewisham hospital and drawing blood from patients. I believe there were no real rules at the time. It was a very relaxed atmosphere and attitude. I'm not sure whether the patients even knew that my mum was just training or whether they even consented.

16. Home treatment for me was the first part of my liberation. Water would be mixed into the Factor VIII bottle, rolled and then injected. It changed my life. If I were to have an accident I would go home and my mum would inject me. I no longer needed to attend a hospital. As a family, it also meant we could now go abroad.

17. I recall one time in the late 70's I had a reaction after receiving an injection – it was similar to having anaphylaxis. I believe it was from a Cryoprecipitate batch. Reactions were, however, considered a side effect. As part of the home treatment training my mum knew to inject Piriton into my arm to neutralise it. In addition, Cryoprecipitate was administered really slowly because you would stop if you noticed a reaction. In hindsight my mum was amazing – she witnessed me having a severe reaction and rather than panicking followed the advice.

18. Around the same time I had a liver function test because doctors suspected a link between Cirrhosis and Haemophilia.

19. I went to secondary school in 1980. It was a very kind a nurturing school – I believe my parent's chose this one intentionally. The school and children knew I had haemophilia. My form teacher told the class to look after me. Some kids just didn't understand it because one day you would be in crutches and the next day you could be playing football. I lived and loved life – I was popular. I do recall one event of bullying but in fairness it was more retaliation. I was told I'm going to die from AIDS because I was a haemophiliac. This comment affected me though.

20. Around 1983 when I was 14 years old I went to Lewisham hospital and I was taught to self inject. This was the next phase of my liberation because you can just get on and live your life. I remember around the same time there were massive adverts in the papers around AIDS. Everywhere you looked it was plastered all over the place. I remember getting a really high temperature and asked my mum whether I had HIV.

21. I remember having a blood test. The doctor also carried out a HIV test and I remember asking him for reassurance that the HIV test was just a formality. Around the time of the test my mum had started to hear stories about contaminated blood coming in from the United States. The doctor then replied as a matter of fact that 90% of patients were coming back positive. I remember being so scared. Your life just flashed before your eyes and your entire future would depend on the results.

22. I remember talking to my mum and asking for reassurance that things would be okay. I remember my mum saying whatever happens we will deal with it. The results took two weeks to be delivered and it was done by post. It was a strange feeling that I cannot properly describe. It felt like waiting to find out whether you had received a death sentence.

23. There was a lot of ignorance about AIDS. If you had it, you were homosexual. There was a huge amount of ignorance and stigma. I still remember coming back from school and my mum said, *"I've got great news, you're negative".* It was miraculous that it came back negative. I have no idea how I avoided it.

24. In hindsight it was pretty unbelievable that such a life changing result was delivered by post but then at the time hospitals were more clinical than emotional. I remember the doctors also did not prepare for the consultations either. They would wait till you were in the room and then phone the lab to get the results.

25. I remember my friend GRO-B was really stressed about a history exam but I was completely care free because the negative result felt like I had been given a second lease of life. Life gave me a toss and I won. In hindsight this is probably why I didn't do as well as I could have done academically.

26. My mum used to go and collect Factor VIII for my home treatment. One time she was given a choice between a heat-treated American product and a non heat-treated British product. Being a parent, I cannot imagine what my mum was going through. It was like playing Russian roulette with your child's life. Depending on the option she chose she could effectively be killing her child. My mum didn't know what to choose but eventually went for the British product.

27. I went for blood tests every six months. A HIV test was also performed. Towards the late 80's when I was around 17/18 more people were coming back negative for HIV so it felt like the odds were in my favour again. At this stage in my life I started dating girls. Luckily I lived in a nice area and it was okay otherwise the stigma would have impacted me massively.

28. I left school in 1988 and went to university. I registered at the local hospital in GRO-B and I was under their care. Nothing significant happened to me during this time. It was the first time I was away from home and I remember having to walk around a lot. This caused issues in my ankles – they had become arthritic. I still remember having blood and HIV tests every six months but by this stage the tests had became routine and it wasn't traumatic.

29. I moved to Leeds after university in 1993 and started to work for GRO-B GRO-B to save money and go travelling. I registered at St James' hospital and they took over my care. Before going travelling I went for my routine bi annual check up. This time they added a HCV test.

30. About 5 days later I got a phone call saying I was positive. HCV at the time was underplayed – a lot lower key than HIV. I remember being told that some people go on to develop cirrhosis but I didn't need to worry about it. I was advised not to drink too much. At the time I wasn't worried – it was nothing like HIV where the fear of death was significant.

31. At the time I was too excited about going travelling so it didn't concern me. I just felt it was just a virus that I could deal with. Not many people understood it either so there wasn't much stigma around it. I tried to get as much Factor VIII as possible for my travels.

32. I remember getting a bundle from Leeds and Lewisham hospitals. When I went to ask Lewisham for Factor VIII I had to see the consultant. The consultant told me not to drink too much, but it was flippant because he knew that's all I would be doing when I went away. At the time there was no real cause for concern though. I don't recall being told anything around transmission.

33. I travelled for a year and came back to the UK in 1994. I hadn't given HCV a second thought and it did not change my lifestyle. I started a

new role in London so I transferred my care to Guys and St Thomas' hospital (GST). I knew one of the nurses there as they had previously worked in Lewisham.

34. GST was a centre of excellence and knew a lot about HCV. I believe at the time they were researching cures. In 1995 their care and service in my opinion was outstanding. You were given literature about the condition – told about transmission i.e. that you couldn't transmit HCV through saliva or sperm. I found this advice really valuable as it helped me protect my family. I kept my toothbrush and razor separate. Prior to 1995 I don't believe I received much information.

Section 3. Other Infections

35. Dr David Bevan from GST sent a generic letter about the risk of vCJD in February 2009. It outlined that a haemophilia patient had evidence of vCJD but did not suffer any symptoms of the disease or pass away as a result of this. It went on to outline how you can reduce the risk of transmitting vCJD on to other people.

Section 4. Consent

36. After 1994/1995 I remember the hospitals would provide me with a lot more information around the tests. Prior to this information was limited.

Section 5. Impact

37. After another routine six-month check I started to realise HCV was not good and was in fact quite serious. Up until then my life had been pretty good. GST started to do liver scans and blood tests to determine my viral load and how to manage the condition. I believe

these tests were not very accurate or precise so they did a HIDA scan to determine the extent of the damage caused to my liver. I believe the results of this were fine.

38. I tried to remain optimistic but felt the claw of Haemophilia had caught me again. I dodged a bullet with HIV but now it had come back and got me again. My moods started to vary. When I had a bad test result I would be down and then eventually recover because over time it stopped being front of mind.

39. For me the problem with HCV was that it was like a silent killer so this made me emotional. As they couldn't do anything to treat it at the time, I had to carry on with life. It was only when the six monthly appointments would come up my feelings would become compounded and I would start to feel anxious. After the appointment you could park them again for six months.

40. I met my wife to be in 1995. In 1996 a nurse suggested that she be tested for HCV. The nurse phoned and confirmed she was negative. I got married in 1998. I had a lot of things going on in my life around this time. I remember I was moved to a new synthetic prophylaxis product. Whilst this meant the risk of contamination effectively went away the joy was short lived, as there was a significant death in the family around the same time.

41. I was attending two clinics at the time – one for my HCV and one for my Haemophilia. My appointments were, however, more focussed on the management of my HCV. Most of the discussions at the clinics were around testing. I would have a test, for example, a Fibroscan and then be informed of the results and the implications. I remember the results hovering around 6. My results are exhibited **WITN0368002.**

42. If the Fibroscan results went up we would discuss the treatment options. At the time the statistics on clearing the virus were not great.

Most haemophiliacs had HCV genotype 1 and drugs to combat this were not very successful. I believe it was Terry Wong at GST who was the main person responsible for HCV and Haemophilia. He would give me an update on new treatment options. He was very clear and direct. I remember once he told me I had 10 – 15 years left.

43. Around the same time my wife and I had a discussion around having children with the Haemophilia nurse. We started to have unprotected sex and I couldn't have treatment whilst we were trying. Our first son was born in 2001. I remember my wife had tests to confirm she was still HCV negative both during pregnancy and after his birth.

44. I started treatment with Pegylated Interferon and Ribavirin Therapy in 2002. The interferon was administered once a week and the Ribavirin was taken as a tablet once a day. I remember having some open discussions around the side effects. Most of which were physical. From memory these were; flu like symptoms, fatigue, weight loss, temperature and thinning of the hair. I was given a booklet that listed the side effects. I was keen to get the HCV resolved so I agreed to treatment despite the long list of side effects. I remember alternatives were offered too.

45. The side effects came about quite quickly into the course. I had a lot of fatigue with flu-like symptoms and suffered from weight loss. My personality changed massively. I started to become much more cynical about life. I became distant from my wife and baby. I feel I just drifted and became isolated – it was like being on an island by myself. I was in a bad mood permanently – I think at the time it was commonly referred to as Ribavirin rage at the time.

46. Doing anything and everything was an effort. In hindsight if my wife and I didn't work as hard as we did, the marriage would have ended. It came to the point where I was looking for alternative accommodation. From a physical perspective it was equally brutal. It

was like walking around with flu and fatigue for more than six months. The weekends were just as bad as I was too tired to do anything. I was permanently tired – I could fall asleep anywhere at any time in any place.

47. I remember being offered support by the community nurse but again was very cynical. I don't think I could really be reached. Six months (24 weeks) into the treatment I had a check up. They told me that the drugs had not worked. I remember the consultant telling me that my viral load had reduced but not cleared so there was no point in continuing the treatment. I felt I wanted to battle on and continue. In hindsight I was in a bit of a fog. I felt like there might be a chance and I had some hope.

48. After realising the treatment was doing nothing I was in a bad mood and my marriage was at breaking point. I stopped the treatment at 28 weeks as I was not responding and went back to the regular testing cycle. They told me that new treatments and ideas were coming out all the time. It felt like I just needed to hang in there until things advanced medically. My wife didn't want me to go on more treatment if there was not a high chance of success. At the time I wrote a poem – that summarised my emotional and mental wellbeing.

Not long to go now,
Nor far to run,
Time is running out now,
The time is going to come.

Can't escape any longer,
Can't avoid the clasp,
The claw of Haemophilia,
has wrapped round me at last.

Feeling so dejected,

Feeling so alone,
No one knows the feeling,
No one hears the groan.

Can't hide it any longer
Can't…

49. I knew my lifestyle had to change. In 2006/2007 I completely stopped drinking. I started to look after myself because it was a waiting game to allow modern medicine to catch up. It was a tough year as people ask you why you do not drink. It was a challenge to explain it to your friends.

50. In 2015 Terry Wong at GST told me about a new treatment (Harvoni – Ledipasvir 90mg and Sofosbuvir 400mg). The drugs were not licenced by NICE, but it had a 95% clear rate. I was told the drugs were very expensive and wasn't available under the NHS but were available privately. I had a conversation with my mum and she said that she would give me a cheque but I thought I would try and wait till it was available on the NHS.

51. In March 2016 I got a call from a nurse to start a new trial. I remember it well I had just flown back from America. They did all the checks and I was signed up to the trial. You had to go and collect the medicine from the pharmacy. They were so expensive and valuable so I remember I kept checking to make sure I had them in my pocket.

52. My viral load decreased massively within two weeks of taking the tablets. In another two weeks I was cleared of HCV. I completed the course. After three months I had a further test to ensure I was still clear. By September 2016 I was told I was officially clear. I remember getting the call as I walked through Singapore airport. It was brilliant.

53. I still undergo the six monthly checks but I remain clear of HCV.

54. From a financial perspective I have to pay extra for Travel insurance as a result of my Haemophilia and HCV. I believe the premiums have fallen a bit since clearing HCV. I do not have life insurance as it is 4 or 5 times the normal price but fortunately I have a death in service benefit with work. I also have a critical illness policy again with work. I am surprised they gave it to me because 14/15 years ago the provider refused me cover.

Section 6. Treatment/Care/Support

55. I remember one incident in 1997 or 1998 where a dentist told me that I had to be the last patient to be treated because they would have to clean / scrub down the room after I left. Other than this I have not had any problems with access to medical treatment.

56. The investigator made me aware of the British Red Cross telephone support service during the interview. I have taken the card and will decide whether to take this up.

Section 7. Financial Assistance

57. I received a lump sum payment from the Skipton fund for £20k. I believe I was told I was eligible through St Thomas'. I now receive a monthly payment of £1500 from EBISS with an additional £500 as a winter fuel payment.

58. I don't think the process was particularly tedious – the form was crude but wasn't difficult to fill in. It felt like you were just given the money and told to be quiet – a way to stop people complaining. At the time, for me it felt like something was better than nothing and that the offer wouldn't be improved. I remember feeling the amount was completely

unfair – they did no calculation based on your age or your circumstances.

59. I remember signing some sort of waiver for legal action. The condition is that you could not claim again even if your health deteriorated or you died. It felt like they didn't want to accept liability. I feel like those responsible for this scandal need to own up to their mistakes and offer victims the appropriate level of compensation.

Section 8. Other Issues

60. I would like the inquiry to publish the truth. People have suffered and died as a direct result of this scandal and potential cover up. Some aspects definitely feel like a cover up. Giving people blood that you know is contaminated is immoral and unethical. I would like to know why the UK plan to become self-sufficient, didn't materialise. Whilst my outcome has a happy ending, it has not been a land of milk and honey and it is something that could and should have been avoided.

Statement of Truth

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

Signed GRO-B

Dated 25t April 2019.