Witness Name: GRO-B
Statement No.: WITN5472001
Exhibits: **Nil**
Dated: 24/06/21

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 18 May 2021.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1970. I live in GRO-B South East London with my mother, GRO-B: M M I have one sister GRO-B I had another sister who sadly died. I am currently unable to work owing to ongoing health problems. Prior to this I was a labourer. I worked in stone masonry for a period of time, following in the footsteps of my granddad. I am single.

2. I intend to speak about my infection with Hepatitis C (HCV) believed to have been contracted either from blood products or a blood transfusion

to treat my von Willebrand disease. I also intend to discuss my mother's infection with Hepatitis B contracted separately from Factor VIII administered during a tooth extraction. She also carries von Willebrand disease.

3. In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment received and the impact it had on myself, my family and our lives together. I will also go on to discuss the circumstances surrounding my mother's infection and the impact this had on her and our family life.

4. I am being supported today by my mother. Some of the dates provided are only approximate as I cannot recall an exact chronology of events. Nevertheless, my mother has helped me to fill in some of the gaps in my recollection of the course of my illness.

Section 2. How Infected

5. I was born with von Willebrand disease. My mother also carried the disorder. I cannot recall the precise date in which I was diagnosed. It was either shortly after a visit to the dentist in Lewisham or after blood tests were taken in relation to my appendix which was then removed. I saw so many doctors at Lewisham Hospital, as I was constantly having blood tests. They were brilliant. I was always given a little room of my own with television and games. My mother was told that something wasn't right. Shortly thereafter, I was diagnosed with von Willebrand's. I

was told that it was something to do with my blood. I was very young and devastated to learn of my diagnosis.

6. As a child, I always bruised easily and suffered with multiple bleeds. I knew when a bleed was coming as my skin started to feel very warm. Initially, I treated these using ice. I was then given tablets which didn't work so I was administered injections by a nurse. She used to come in every day. I experienced flu-like symptoms. I don't remember the names of the products in which I was given. It was so long ago and I was only young. The clotting factor in my blood isn't so bad as I've gotten older, but I am unaware of the exact percentage.

7. Growing up, my school life was difficult. In primary school, I had trouble with reading and spelling, and the teachers were not helpful or supportive. I was often getting into fights which led to me getting expelled. I joined another school which was even worse, so much worse that I was even hit by one of the teachers. I left school when I was 15 due to persistent bullying. I went into labouring and became a stone mason, which they trained me to become whilst on the job. I am proud to say that I was involved with the creation of the dolphin sculptures in Trafalgar Square and I worked in this role for two years.

8. In my early twenties, I lost a lot of weight. My mum can recollect this. I went to the Lewisham Hospital for blood tests; this was just a routine appointment, which I had gotten used to as I'd been in and out of hospital for most of my life. To my surprise, on this occasion they called

us back to tell me that I had Hepatitis C. I was informed that this could have been contracted from the Factor VIII products which I had received throughout my teenage and adult life.

9. I have not used intravenous drugs nor do I have any tattoos. Therefore, I firmly believe I contracted the virus through the transfusion I received for either my appendix or my tooth extraction. The Factor VIII products are also a potential source of infection and in my opinion, could have been contaminated too. I would have liked to have a tattoo, but the minute I found out about my infection, I avoided disclosing it; I was so ashamed.

10. I was told that the virus affected the liver and was not given much more information. I was so shocked to hear that I had been infected and all I wanted to know is what they could do to get rid of it, so I asked. They said they would keep monitoring me because there was no treatment available at the time. They didn't give me any advice about how to deal with potential contamination or the risks of transmitting the virus to others. My mum supported me by asking the hospital a lot of questions; in particular we wanted to know about whether the virus could be transmitted through sex. We also learned that teeth brushing was a potential risk factor and tooth brushes were therefore not to be shared.

11. I was referred to a liver consultant, Dr John Donohue. At my appointment I don't remember being given any information about

prospective treatment, they just continued to monitor my viral load. At the beginning I remember that it was really high, in the '7s' if I recall correctly. My mum accompanied me to all my appointments, helping me to understand things better, as I struggled to do this alone. At some point during one of my treatments, which I will go on to discuss in further detail, I had a biopsy on my liver which revealed scarring. I was told that I was on the precipice of liver cirrhosis.

12. I wish to add that my mother M was also infected with Hepatitis B. Her date of birth is GRO-B 1948. She has lived in GRO-B since 1992. She is also a carrier of von Willebrand disease. In the mid to late 1980s, she had teeth extracted for which she was given Factor VIII. Quite a while later, when I was around 16 years old, she was called into Lewisham Hospital. She was told by the doctor, who is now retired, that she had been infected with Hepatitis B and that the other three patients who had a teeth extraction operation on the same day as her, had also caught the virus. After the operation, she was jaundiced and her skin turned very yellow.

13. My mother recalls that the staff at Lewisham Hospital were more concerned about the doctor who caught the virus on the same occasion. She was not provided with a great deal of information other than that she had caught the virus from the Factor VIII she had been given when her teeth were extracted. She was told that treatment was not available and that her condition would merely be monitored.

14. In the end, my mother was never offered treatment. Her condition was simply monitored. She states that at one point, she was so jaundiced, she looked like a number plate on a car. I can remember it distinctly too. The yellow tint diminished over time. Although, she was warned that it would return. She was never advised of the risks of transmitting the virus to others. However, she took her own initiative to be careful and miraculously, she cleared the virus naturally.

Section 3. Other Infections

15. As far as I am aware, I was not infected with any virus other than Hepatitis C. My mother was not infected with any virus other than Hepatitis B.

Section 4. Consent

16. Neither myself nor my mother were given any information about the risks associated with either the transfusion I received or Factor products used to treat my von Willebrand disease.

17. My mother was never warned about the risks involved in the Factor VIII she was given when her teeth were extracted.

18. Whilst I consented to the blood tests I received to investigate my health prior to my diagnosis with HCV, I did not specifically consent to be tested for the virus.

Section 5. Impact

19. I found out that I was infected with HCV in my twenties. Prior to this, my health wasn't too bad. I did experience bouts of weight loss which might also have been caused by stress, but it was significant as I dropped to about 50kg. I also had intermittent pains in my abdomen. In retrospect this could have been caused by the HCV which went undetected for several years. My health really started to go downhill around twenty years ago when my back problems began.

20. When I found out about my Hepatitis C, I felt depressed and suicidal. I tend to keep my feelings to myself and let things bottle up. I had tablets ready on one occasion, but I stopped myself because of my mum. She has been the only one there for me. During a consultation with Dr Donohue, I was referred for therapy. I didn't find this helpful. I knew the therapist didn't have the virus and therefore didn't understand my predicament. I started to drink heavily after this.

21. After my diagnosis, my mother was so worried about me. My viral load was escalating and I was also becoming increasingly reclusive. When I was experiencing suicidal thoughts, she would check up on me every night.

22. I have since given up drinking as I didn't want to make my liver worse than it already was. I continue to experience suicidal thoughts, and there are times when I feel that my life is worth nothing. However, I don't think I would go ahead with it. It's hard. I take it one day at a time.

23. Overseen by Dr Donohue at Lewisham Hospital, I began my first course of treatment. I do not remember the exact dates although my mum seems to recall that this was available around six months after my diagnosis. I had to administer the Interferon injections in my stomach once a week. I was also given tablets. I was told there could be side effects, but I was not given any indication as to the severity.

24. The first treatment was terrible. Within two or three days, I started to experience the shakes and shivers - it was just horrific. At two or three in the morning I would have to sit near the fire in the living room. I experienced severe stomach pains, night sweats, loss of appetite, insomnia, and severe depression. I continue to have problems sleeping as a result of the pain in my back. The side-effects were so serious that the course was terminated prematurely. After this, I calmed down and my mental health improved somewhat.

25. During the first treatment, I was still in my twenties and held out hope that I could still have a family if it was successful. When this failed, I was very upset. Shortly after, I started a second course of treatment which lasted a year. I was in my thirties at this point. When I returned to the hospital for further blood tests, I learnt that it had not been successful.

26. When I learnt that I had not cleared the virus, my mental state took a drastic turn and I really went downhill. The prospect of starting a family

was rapidly disappearing. My back problems were also getting worse. I just questioned whether it was worth going on with all this stress.

27. Discussions about the state of my health and ongoing treatment took place primarily between the hospital and my mother, because my memory is not very good. I can't even use a mobile phone because I forget my phone number and password. On one occasion, I smashed my phone with frustration because I couldn't remember the password. I have to keep a note of my number in my wallet.

28. They told me to wait for the third round of treatment, which consisted of a combination of injections and tablets. I am proud to say that this was successful. I was 42 or 43 when I cleared the virus. The side effects were similar to previous courses of treatments, albeit less severe. It was unpleasant but more manageable. My stomach couldn't tolerate food. I experienced stomach aches, constipation, and sweats.

29. As a schoolboy I was muscular, but when I caught hepatitis, I began to lose a lot of weight. I think this is also caused by stress and excessive sweating. I was prescribed milkshakes in order to put on weight, but these did not work. I'm also on morphine for my back pain together with sleeping tablets for my insomnia; I don't sleep at all. I can go four nights without sleep. This has been ongoing for at least twenty years.

30. For a long time, only my mother knew about my infection. The rest of the family didn't know nor did my employer. In fact, I didn't tell my

family for seven or eight years until my health really deteriorated. They were understanding, despite my feeling that I had the plague. I didn't want to experience the paranoia of wondering what others would be thinking. I was also frightened that I was going to give it to them. If I had a bleed, I would be very cautious.

31. When I told my dentistry practice about my Hepatitis C status, I felt as if they treated me differently from thereon and kept a distance. They wore full masks and informed me that I would have to attend the special care unit at Lewisham or Guy's Hospital for any future dental treatment.

32. My von Willebrand never stopped me from working. I had to be careful if I fell and had a bleed but other than that, it didn't affect me. However, I am now unable to work due to ongoing back problems. This was initially treated with steroid injections at Lewisham Hospital, however, these were not effective.

33. During one of my hospital visits, another patient noticed that I was struggling to walk around the hospital and he recommended that I go to St Thomas' Hospital for a scan. I thought that was sensible and decided to have a scan at St Thomas', which revealed that one of the discs in my back was protracted. I was told that this could have been caused by heavy lifting. I would like to go back to work but I am unable to do so. Whilst I have not been told that the HCV could have contributed to the problems with my back, I believe it may have had an impact.

34. When I was working in stone masonry, I was planning to buy a house in GRO-B but then I fell out of work due to the pains in my back which prevented me from working any longer.

35. Before I was diagnosed with HCV, I had a girlfriend. When I discovered that I had been infected, I knew that I had to tell her. I was aware that we would have to be careful with sex and wear protection. I was devastated because I knew this meant that I couldn't have kids. I was reluctant to tell her at first because I really liked her and was worried about her reaction. She responded, '*Oh, is that like AIDS*?' She then said that she was really sorry but that she couldn't be with me anymore.

36. Losing my relationship and the prospect of starting a family led me to start drinking. When I used to go out with friends, they would be chatting to girls and I instead I would just drink. I felt like I had to be the funny one and use humour as a defence mechanism. I stopped socialising soon after. I don't see anyone or go anywhere anymore. Missing out on the chance to have a family is a continuous source of pain for me. Seeing my niece, my sister's son, is very painful. In all honesty, I now feel as if I don't feel I have much to live for.

37. My mother felt a bit down when she was diagnosed with Hepatitis B. The NHS had given her this virus and yet they could do nothing to rectify their actions. She told me but not my siblings as they were too young. She had three children to take care of by herself, whilst working

full-time as a cleaner. She didn't tell her employer. She says, '*I was an old scrubbing woman. It didn't have an impact on me. I had kids, I just got on with it. I had to.*' She now has severe arthritis for which she needs a shoulder operation. However, she was told that there is a significant possibility that she won't survive the operation.

Section 6. Treatment/Care/Support

38. Around three to four months ago, I was in hospital with a really bad chest infection. I was being given a blood test when the nurse accidentally inserted the needle into my vein and then into her own. Shortly after, she looked at me and asked why I hadn't told her that I had Hepatitis C. I told her that I had been given the all clear some years ago and that I was advised that it wasn't necessary to mention it any longer. This nurse told me that this was wrong advice. I was gob-smacked. I didn't know what to say. I was then told that I would need to have more tests.

39. After further tests, I was told that there was still something wrong with my blood. I was confused because as far as I was aware, I had been cleared of the virus. I thought, no way have I got it. The nurse told me that she would contact me the following day. When she did not contact me, I visited the ward only to be informed by another nurse that she wasn't there. She was so rude and dismissive that I started to lose my temper. I continued walking through the ward and spoke to the original nurse who was allegedly not in the hospital that day. She told me that I

would need more rigorous testing. I went the following week where I was told that I had hepatitis antibodies. I am confused as to the state of my HCV status as I feel that I have been given conflicting information.

40. I might have been offered psychological treatment through letters in the post but I don't remember. I was too overwhelmed with the diagnosis to think about this. It was too much to handle.

Section 7. Financial Assistance

41. I found out about the Skipton fund through my mother who received a phone call from Lewisham Hospital to the effect that I might be eligible. They sent me forms. My mum dealt with all the forms as I cannot read or write. She tells me that she found the process reasonably straightforward. I cannot fault them. There were no difficulties in obtaining payment.

42. I received a first payment of £20,000. I now receive £4,000 every 3 months. Whilst the money is helpful, it doesn't change anything. The virus has had a devastating impact on my life and no amount of money will change that. No amount of money will change the fact that I cannot have children.

43. My mother has never been informed that she might be eligible for financial assistance from Skipton or any other trust or scheme.

Section 8. Other Issues

44. The impact of being infected with HCV through contaminated blood has been enormous. I want kids more than anything. It gets me down a lot to face the fact that having a family is no longer a possibility. When my mum dies, I die. I don't want to live anymore at that point. I'm not going to live as an old man on my own. She knows that and she can't do anything about it. That's my choice. I've seen on the news that blood was being imported into the UK from prisoners in the US. I think this is awful. I want the Inquiry to find out how this was allowed to happen.

Statement of Truth

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

Signed GRO-B

Dated 24/06/21