Witness Name: GRO-B
GRO-B
Statement No.: WITN5546001
Exhibits: Nil.
Dated:

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 29 March 2021

I GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1973 and I reside in GRO-B and my full address is known to the Inquiry. I live with my wife GRO-B and our GRO-B year-old son, GRO-B

2. I am a trained engineer in motor vehicles and electrics; CCTV and other similar systems. Recently, I set up my own business, called GRO-B which provides an array of services for alarms, CCTV systems, and cars. In the past I worked as a technical engineer for GRO-B and on HGV for Hovis, then known as Mothers Pride, and then for Vauxhall.

3. I intend to speak about my infection with hepatitis C (HCV), which I contracted from Factor VIII blood products. In particular, the nature of these illnesses, how they have affected me, the treatment received and the impact it had on me and my family.

4. I can confirm I am not legally represented and I am happy for the Inquiry Team to assist with my statement.

Section 2. How Infected

5. At nine week old, my parents found out that I had haemophilia with a 3.5% clotting factor, which was identified as moderate to severe. I used to bleed very infrequently. At 18 months I banged my foot and at 2 and half I fell on some ice and hurt my shoulder. My parents practically wrapped me in a ball of cotton wool.

6. My mother was always worried about passing it on and before I was born my parents looked into adoption. She was terrified to pass on a condition that she had watched her father suffer with. In those days haemophilia had no treatment, so they just let you bleed; I remember my granddad with rolled up fabric in his mouth to stem the bleeds from tooth removal.

7. During my childhood I was mainly treated with cryoprecipitate under the care of Dr Evans at Manchester Pendlebury Hospital. When I needed treatment, it was always a tedious job, as when I got bigger, the quantities of cryoprecipitate increased drastically. At age four or five I would need at least four bags of cryoprecipitate, which would require defrosting before being used to treat my bleeds. I also felt that there was a huge disconnect amongst the hospitals I was treated at; once when I was at Lancaster Haemophilia Centre, they put me on a drip for five hours, which was rather strange.

8. I slowly came off cryoprecipitate and moved on to small vials of factor VIII. I recall at the time that the doctors told my parents it was difficult, almost impossible to get hold of heat-treated factor products. It was not long after

I moved on to factor products, that the team at Pendlebury were suggesting to my parents that I should move over to home treatment, but my parents were suspicious and completely against it. This was in the early 80s, as there was an awareness of AIDS in the media and my parents thought it was riskier to administer products at home.

9. Pendlebury hospital encouraged prophylactic treatment; my cousin, who also was infected with HCV from factor products, was on this type of treatment. It was very much a treat, but no cure ethos.

10. It was not until I went on holiday to St Ives in Cornwall that I believe I was given infected blood. Whilst I was away, I required treatment and was sent to Truro Haemophilia Centre to receive it. When I returned home, I became infected with what was thought was jaundice and was very ill, spending a week at home. Then eventually, being taken to Wigan Infirmary and isolated for a week. It was not clear what I had and the Doctors' thought I had jaundice, which is why they isolated me, doctors were giving me injections and they were not supposed to and when we contacted Sister Shaw at Pendlebury she demanded that I was transferred to Pendlebury.

11. I officially found out that I had HCV in 1984-1987, which I believe is what I contracted when I received treatment in Truro.

Section 3. Other Infections

12. When I found out about the HCV. I was also told that I could have HIV, as it was all portrayed and passed together. Despite this, and despite suffering with the stigma associated with both infections, I do not believe I was infected with anything, other than HCV. Regular HCV check-ups were carried out and I was told that I had a positive test at ten years old, around 1980.

Section 4. Consent

13. As I was a child when I received most of my treatment, I would assume that my parents consented to my treatment, although I cannot say for certain that they did. All advice was given at Pendlebury hospital.

Section 5. Impact

14. Finding out about my HCV was a complete and utter shock and it came at a time where I had only just started dating GRO-B. We had been intimate, so it was very difficult to tell her that she needed to go into hospital for a blood test and that I may have infected her with hepatitis, which I knew nothing about. Her mother was also upset, as they were both completely unaware of what HCV was and the implications, as was I. It was most definitely not ideal for a blossoming relationship. Despite this, we stayed together and took precautions until we had our son and I was clear of the virus.

15. It was also particularly challenging as AIDS and HCV came out at the same time and the stigma came with it too. We kept it from our family and friends and I kept it quiet from work. Alongside the haemophilia, it was all such a taboo; people believed that a haemophiliac would bleed everywhere and infect them.

16. I would say I always attributed the symptoms I experienced over the years to my haemophilia; brain fog and joint pain. It seems that through following the Inquiry, I have in the last two years become more informed about the symptoms of HCV, than ever before. I believe that the symptoms I experienced were most likely the HCV, rather than my haemophilia, or at least a combination of both.

17. I also suffered lots of problems with my arm, which often brought my wife and I to tears during the sleepless nights in agonising pain. Haemophilia is a hidden condition, until you have a bleed it's relatively unimportant, but

then when it happens, it's like putting your hand in a steel vice. It seemed to me that I also suffered from rheumatoid arthritis, at least since I turned 40. I knew the pain I experienced was similar to that caused by the arthritis, and I felt it most in my shoulders and toes, but it was dismissed by the consultant at Liverpool.

18. When I was eventually offered treatment for my HCV, I was told it would be like cancer treatment. It was truly horrendous; I remember shaking after the first injection and cannot forget the lingering taste of the treatment. I was on interferon injections weekly and ribavirin tablets daily; they both sucked the life out of me.

19. Despite the struggle I endured with taking the HCV treatment, I worked through all of it, learning to adapt to the pain and all the other side effects. I barely took time off; in fact, I only took two days off in the 12 months whilst on the treatment. Part of the reason I didn't take time off and took hospital trips or sick days as holiday, is because I kept my haemophilia and HCV a secret from my employer. In my field, it would have been impossible to convince your employer to insure you when you had haemophilia and HCV. Those 12 months of treatment in 2009 were some of the hardest in my life and to this day, I've never got that strength back.

20. I felt that telling the truth would hold me back and stop me getting to the top, although I believe my haemophilia health was the real underlying reason, I didn't reach the top. There were opportunities in my early career that I turned down, like going to Spain as a car garage owner.

21. During my treatment, I suffered from bouts of depression, and have since been up and down. At one point I spoke to a Doctor about this, as I had been having suicidal thoughts, and I was prescribed antidepressants. In 2017 I had a breakdown at work and ended up at my GP practice in a hysterical state as I could no longer cope with the problem. They offered a mental health service through an application on my phone. I didn't feel any benefit from using it. I didn't log in anymore, it is a surprise to me that they

didn't chase me to see how I was. I have heard nothing to this day. This event led me to retire in 2017, despite loving my job and not wanting to leave.

22. I also had major issues with my knee and have had three knee replacements. On one occasion my knee exploded due to an infection and I spent about a month in hospital.

23. The hardest thing for me is that I feel as if I have a split personality; it's like the part of me that had HCV is another person. I was hiding from it all. It hit me the most when we had our son, because I couldn't run around with him and do the sorts of things a father would do with his son.

Section 6. Treatment/Care/Support

24. Until I was 18 years old, I was treated and looked after at Pendlebury Children's hospital. I remember seeing a nurse called Sister Alex Shaw, who was a very special nurse to me and acted as a mother and father figure to every patient there. It was clear that she always wanted the best for her patients; arguing our corner and would often give us back handed advice. In my mind, I don't think she would have administered any products that she knew to be risky.

25. During the years I visited Pendlebury, I also visited a clinic called GRO-B GRO-B which focused on treatment and care for haemophiliacs and was run by Dr Evans. Every 12 months I would go for a general check-up where I would also receive dental and physiotherapy check-ups; it was quite a good establishment and I felt they paid you the attention you deserved.

26. Whilst I was treated at Pendlebury, Factor VIII was presented as treatment for which the benefits outweighed the risks. I recall it only taking three to four minutes to make up and administer, which was revolutionary in

comparison to the cryoprecipitate. It was also a miracle that it treated your bleeds in less than 24 hours. I must say that Dr Evans was picky about the products being used there, but we very rarely knew what we were being given; the brand names would often change, although the name Refacto seems to ring a bell.

27. My treatment team were adamant that I should be moved onto home treatment and a more prophylactic style of dealing with bleeds, but my parents contested this; my mother would often have arguments with Dr Evans regarding this. Despite this, I was treated well there and they slightly bent the rules for me, as I stayed there till I was 18 years old although it was a hospital for children.

28. After leaving Pendlebury, my treatment has been somewhat below par. I found out I was HCV positive following an unexpected phone call, where I was told to go into hospital for a blood test and to bring all the individuals, I had sexual relations with in the past. Up till this point, I was completely unaware my infection could infect others. It seems a considerably long time to live with the truth unknown, given that it was likely that I was infected with HCV when I went on holiday to Truro.

29. When I found out about my HCV, I was given no information about the side effects of the infection. I was only told that I should have frequent blood tests, every six to 12 months. Initially that was all the Doctors' recommended, and it was not until much later that treatment was discussed. I recall my liver function tests coming back as normal and that no biopsy was ever performed; there was very little medical intervention at this time.

30. I believe I was offered treatment for my HCV in ~~2009~~ 2006, but my wife and I were trying for a baby and we were advised to delay the treatment until after we had conceived. We also spoke to the Doctors' about having children and the risks involved, but there was not much fuss made, so we went ahead.

31. After my son was born, I waited a while before starting treatment just until he had started sleeping through. I was advised it may cause tiredness back then I had no awareness that I was suffering from any symptoms of HCV, so it didn't seem necessary. It has only come to light since following the Inquiry, that I was most likely experiencing different symptoms of HCV. In any event, I was told that since I had no symptoms and the Hepatitis C lay dormant in my body, it would only cause problems if it later developed into cirrhosis. They did say that it would be beneficial to treat early.

32. I began treatment in 2009 and I was told that I would start the course of interferon and ribavirin for three months with the outlook of continuing for six months, and if beneficial, then extended to 12 months. After a month into the treatment, my viral load reached the level they thought it would for the remainder of the treatment, but I still had to persevere with the horrendous side effects, until the remaining time was complete.

33. Following my treatment and since I turned 40, my health deteriorated and I was in and out of hospital for various things. I regularly attend Liverpool Royal Hospital for general check-ups, which is handy if you have something to discuss with the consultant, but if you don't, then it is really a waste of time; a two-hour drive round trip for a 15-minute appointment.

34. I also suffered with an infection of a knee implant, which led to my knee cap bursting and me spending a month in hospital. Whilst I was in hospital, I was having problems with the pain killers they were prescribing me; I didn't think the tramadol was working, but they did nothing about it. At one stage a lady came and spoke to me about being involved in a study that would identify which medication is most suited to your specific genome. I decided to partake and eventually found out that, funnily enough, tramadol was a pain killer that does not work for me. It took me 14 days to make the hospital change my painkillers, which eventually they did.

35. The other palaver I had to deal with was having regular blood tests whilst having a total knee replacement (TKR). With my complaint many more blood tests are needed and with what seemed to be ill trained staff were

being employed for the role. One staff member had four goes at taking blood before conceding defeat. The main problem is most patients leave hospital and the use of their veins returns to normal, ware as my veins carry on being attacked for several months later so the more effective at taking blood the better that meant a hick line would be far more efficient and on my return to have a second TKR to the same leg I had one fitted. However I then discovered that phlebotomist are not allowed to take blood from the line so I found myself in a similar position once again. Whilst being in for the third time due to infection in the TKR I ended up having a hick line that I used to administer my own medication and also take blood as staff were not available to take the blood early enough to get results back to give my treatment, I therefore ended up doing most of it myself.

36. Eventually I'd had enough, so I decided to research the procedure in cleaning a hick line, and managed to get all the equipment myself. I ended up treating myself whilst in hospital, working through the steps which were required to complete the procedure properly. What is surprising is that the nurse that had done this before, didn't complete some important steps i.e. changing the end cap after having removed it. It seems crazy to me that I knew the procedure and could treat myself better than the staff at Liverpool. I attended Liverpool Royal Hospital each week to have my line maintained they had to change the dressing on it, most of the time the hospital didn't have to correct parts and found staff scrabbling about to make do

37. My situation was brought to the attention of the Matron and she was not pleased that I was treating myself, but I explained why and that due to the incompetence of her staff, I would continue doing so, as it was in my best interests.

38. In respect of my dental treatment, I would mainly utilise the services at Liverpool hospital, as I had to declare my HCV status at my local dentist surgery. I remember attending my local surgery a few times and seeing that HCV was written on all of my papers; it was much easier to go to

Liverpool hospital, as I didn't have to deal with this. I used to make excuses about being nervous and they would send me straight to Liverpool. I attended my local surgery after completing my HCV treatment and have since noticed the HCV writing on my papers is now crossed out; I am proud to say I don't have it.

Section 7. Financial Assistance

39. My aunty GRO-B told me about the Skipton Fund, as my cousin had been successful in his application. I decided to apply in 2009 and I received a pay-out of £20,000.

40. It was relatively easy to apply; I filled in the forms and obtained the relevant medical supporting documents. Nevertheless, I still had to chase them, which I don't think is the right way to do things.

41. I also receive a monthly allowance from EIBSS, which I applied for in 2017 and had no trouble obtaining.

Section 8. Other Issues

42. Obtaining life insurance and a mortgage was another obstacle to overcome. I had to declare my HCV and haemophilia, and I knew the likelihood of getting either was slim to none. In all honesty, I couldn't be bothered with the hassle, but in the end I persevered with a mortgage and disclosed my HCV, not my haemophilia. Also with Covid here I cannot see me having my jabs because of a lack of trust in the NHS. They told me it was all good in 1980 ! it didn't seem so.

Statement of Truth

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

Signed GRO-B

Dated 12/7/21