Witness Name: GRO-B
Statement No.: WITN0937001
Exhibits: **nil**
Dated: 05/08/2019.

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 22 July 2019.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1947 and my address is known to the Inquiry.

2. I am divorced with two children and four grandchildren. My children do not live far away from me; one lives in GRO-B and the other lives in GRO-B.

3. I am retired, but I previously worked for the GRO-B GRO-B in the NHS.

4. I intend to speak about my infection with Hepatitis C (HCV) through a blood transfusion. In particular, the nature of my illness, how the illness

affected me, the treatment I received and the impact it had on my family.

5. The process of anonymity has been explained to me, and I have opted to remain anonymous.

Section 2. How Infected

6. My first child was born in 1973 in GRO-B Maternity Unit, GRO-B Prior to the birth, I was told that I had a narrow sub pubic angle, and that the baby was very large. However, as far as I am aware, this was not taken into account and resulted in me having a horrendous birth and needing an emergency caesarean. The baby was 9 pounds 7 ounces.

7. I am not sure which consultant delivered my first baby, as it was a very long and complicated delivery, so an emergency caesarean team were called in at the last minute. My medical notes do not say that I received a transfusion at this time.

8. 5 years and1 month later, on GRO-B 1979, I had my second child at the GRO-B Hospital on GRO-B Dr Pentecost was my consultant obstetrician. This hospital has since been demolished and a new hospital was built on GRO-B in GRO-B

9. For my second child I arranged to have a caesarean in advance, to avoid another traumatic birth. I also planned to have a sterilisation procedure straight after the caesarean, while I was still in the operating theatre.

10. When I came around from the caesarean and subsequent sterilisation, I was already back in the ward, so I did not actually see the blood I was given going into my body. All I remember from when I woke up was the

nurses surrounding me and feeling raw from the caesarean. I was discharged from the hospital on the GRO-B 1979.

11. According to the clinical report by the Maternity and Child Welfare Department dated GRO-B 1979, it was during the sterilisation procedure that I received two units of transfused blood. I believe this report was sent to Dr Brown by Dr AF Pentecost on GRO-B 1979. When I had discussed the sterilisation with Dr Pentecost prior to giving birth, I was not told that I would need to have a transfusion, nor was I provided with any advice or information about the risk of being exposed to infection during this procedure

12. I do not have any tattoos. I have never used drugs or engaged in promiscuous sex. I did get my ears pierced in the 1980s.

13. On 12 March 2018, I went to see my GP because I had experienced heart palpitations the night before. My GP at the time was Dr GRO-B at the GRO-B Surgery. He wanted to give me antidepressants but I refused – having worked in mental health I knew that I wasn't depressed. Dr GRO-B also noticed that I had an essential tremor and prescribed some beta-blockers to help with this.

14. On the 20 March 2018, Dr GRO-B referred me to some nurses who did an ECG and various blood tests. On the 26 March 2018, Dr GRO-B gave me the results of blood tests that the nurses had taken the week before. The results of the ECG had also come back, and Dr GRO-B said he thought that I had had a heart attack. I said 'surely I would know if I had had a heart attack?' However, he ultimately sent me to see a consultant to confirm his interpretation of the ECG.

15. On 3 May 2018, I had further blood and cholesterol tests. A week later on the 10 May 2018, I visited the consultant cardiologist about the ECG. He told me that I had not had a heart attack, but that I did have a

leaky heart valve. He said that this was not unusual in older people and did not prescribe me any medication for it.

16. On the 11 May 2018, I received a phone call from the surgery saying that while Dr GRO-B was not seeing any non-urgent patients, he would like to talk to me about my most recent blood tests. A few days later, on the 14 May 2018, Dr GRO-B rang up and said that one of the blood tests he had done showed that I had elevated liver enzyme levels, which indicated that I had Hepatitis C. Dr GRO-B asked if I had ever had a blood transfusion. I had not been aware that I had received a transfusion, but jumped to the conclusion that if I had, it would likely have been during my first traumatic birth. He told me that I needed to see a consultant at the local hospital, and said 'you are well though, aren't you?' This all happened in a phone call that lasted about 4 minutes. He did not follow up my diagnosis with a letter.

17. I do not think that Dr GRO-B was a bad doctor; I think that he was just very busy and had too many patients. He did not give me any information at all about the Hepatitis C or how to manage the infection – I found all of this out online by myself. I definitely think that Dr GRO-B should have asked me to come to the surgery to give me the news, instead of doing it on the phone. I also think that I should have been given literature and advice about the infection and how I could take care of myself.

18. Dr GRO-B retired on GRO-B 2018, and I was left without a GP. I had to wait until the GRO-B Group found all of his patients a new surgery. Eventually I was told that I would be transferred to the GRO-B Practice in GRO-B.

19. On 26 July 2018, I saw Dr GRO-D the consultant Hepatologist at The Maidstone and Tunbridge Wells NHS Trust. I took my sister with me for support, because if I had been married my husband would have come with me, and if I missed something my sister would pick up on it. Dr

GRO-D was not welcoming and did not appear to want another person there to put me at ease. Dr GRO-D said that my GP had done all of the 'detective work'. He took me onto a couch in his room, felt the area near my liver, wriggled my wrist and pressed my shoulder. He said that he would put me in touch with a specialist nurse, who I would come and see in the future.

20. Dr GRO-D asked me if I had any questions. I had been to Turkey 5 years before and had ended up in hospital with cystitis. I had been put on a saline drip, and thought that I might have picked up the Hepatitis C from a dirty needle whilst I was in the hospital. The consultant said this was unlikely. I asked him how I picked it up, and when he mentioned the blood transfusion I could not really remember having one because I was out cold at the time. I thought that I might have had the transfusion during my first emergency caesarean because it was so traumatic. However, when I later read my medical notes, it said the transfusion occurred during the sterilisation in 1979. I asked him what my blood group was, but for some reason he brushed this question away and did not answer. I later found out my blood type when I got my medical notes.

21. Dr GRO-D said it was likely that I had lived with the virus for decades, and that although my liver appeared to be okay I would need to have a scan and see a specialist hepatlogist nurse. The nurse would review my scans and decide what treatment was most appropriate. He told me to come off of the beta-blockers I had been taking for my essential tremor. Dr GRO-D did not impress me because I thought that he lacked empathy.

22. I went to see the specialist nurses for the first time on 18 September 2018. The first thing they said was that I must have had a huge shock when I was diagnosed with Hepatitis C. This was the first time anyone had acknowledged how shocking the whole situation was for me. They were very nice and answered all of the questions I had. I asked them

what to do about holiday insurance, and they advised me that I should declare my illness. I asked whether I should take my medical notes with me when I went on holiday, but they said that this was not necessary. I asked them if there was any one else around like me – someone who had the virus, but felt completely healthy. The nurses were willing to put me in contact with someone to talk to or a support group, however as the conversation progressed I felt a bit overwhelmed and just wanted to get it over with and leave. I also asked them how it was possible that I could have had the virus for such a long time without knowing. They said that I would only know how long I had the virus for if I had my medical notes, so they suggested that I contact the Patient Advice and Liaison Service (PALS) to get my medical notes. They also said that they were obliged to let me know that I may be able to get financial compensation, but that I would need evidence to show that I got the virus through a blood transfusion.

23. The specialist nurses did a fibroscan and the result was 7.7. Anything under 10 is good, apparently, and they did not find anything wrong with my liver. They also did a test to determine my genotype, which would help them determine the best treatment for me. My genotype is 1A, and they suggested treatment with Harvoni. I asked the nurses if there were any side effects from taking the treatment, and they said that while it was easy to tolerate, in some cases people did experience side effects such as headaches. I also asked them how long the treatment had been available for and they said that it had been on the market for about two years.

24. I decided that I did not want to take the treatment, and told the nurses that I was taking alternative medicine. They understood my reluctance, because I was feeling well and did not want to take any risks. They said that while the alternative treatment would not harm me, it also would not cure me. I was told that the virus was stable, so if I did not take the Harvoni, the nurses would monitor me every six months by doing blood tests, ultra sounds, and possibly another fibroscan.

25. I spoke to the nurses on 23 July 2019 and they said that there are five indicators they consider when looking at liver health. They said that four of mine are right and one is wrong. However, I do not think that anyone has mentioned cirrhosis of the liver.

26. While the specialist nurses answered all of the questions I asked, they did not give me any further literature or explain how the virus could be transmitted to others. In fact, the only person who sent me any literature to read on Hepatitis C was Samantha May from the Hepatitis C Trust. She has been most helpful.

27. I did think it was odd that the virus had not been detected in the entire 40 years that I have had the infection. I had a Dilation and Cutterage procedure (D&C) during this 40-year period, so I definitely had other blood tests during this time. My only guess is that they were not checking for HCV when I had the other blood tests.

Section 3. Other Infections

28. I have only been infected with Hepatitis C. I have not been infected with any other infections as a result of blood or blood products

Section 4. Consent

29. I do not believe that I have been treated or tested without my knowledge or consent.

30. I do not believe I have been treated or tested for the purposes of research. Although I have not always been told why they are taking blood or specifically what they are testing it for when I have had routine blood tests, I do not suspect that it has been for the purposes of research. However, when I recently had a blood test, I made sure that I asked them what they were taking the blood for.

Section 5. Impact

31. My initial reaction to my diagnosis was fear. I thought that I was going to die earlier than I would have expected. Even now, my tummy turns when I think about it. I get butterflies in my stomach when I think about the infection, because I constantly feel like I have a decision to make: either go on as I am now, without treatment because I feel fine, and risk getting very ill later on, or take this medication that has only been on the market for a few years. It feels like the sword of Damocles is swinging above my head constantly.

32. I requested another blood test later in July 2018, because I was still in disbelief and I had read about false positives and thought maybe this was the case. It did not help that the time between seeing doctors, consultants and nurses was so extensive – each stage took weeks. I lost so much weight around this time, because it was constantly on my mind and I was so worried and terrified. I lost about a stone during this period and went down to about 8 stone 10llbs. I really think that the lack of information had made this so much worse. For example, when I was first diagnosed I thought that if anyone touched my blood, or if I had a nosebleed and it got on someone else, they would catch the virus.

33. After a few months I decided to stop dwelling on it; I didn't have any symptoms and I just wanted to live everyday to the fullest. I decided to start thinking about the steps I could take to manage the virus myself. This was when I started to research things online, because I had not been given any advice from any of the doctors or nurses. I read survivor letters and accounts, which were very traumatic. I looked up information and tried to glean what I could do to make the situation better. I have never had a particularly bad diet, but I tweaked it to make it better. The internet said that you should not drink alcohol when you

have Hepatitis C, to avoid damaging the liver. Although I am not really a drinker, at the time I completely cut alcohol out too.

34. While looking online I found out about the Hepatitis C Trust and decided to ring them up to let them know that I may have contracted Hepatitis C through a blood transfusion. Samantha May from the Trust was so helpful – she spent over an hour on the phone with me and sent me my first and only pieces of literature on the virus and how to manage it. Samantha May also gave me information on how the virus could be spread to others and explained that blood-to-blood contact was required – she told me that I would not pass it on if someone just touched my blood, but rather my blood would have to be on something sharp, and that person would have to prick themselves with it. She also sent me information about the England Infected Blood Support Scheme (EIBSS), and a form to apply for compensation. I had also read about the Inquiry, so I wanted to add my name to the list to ensure that they know how many people have been infected with Hepatitis C through blood and blood products at the end of it. Samantha May passed my details on, and it snowballed from there really.

35. While I do feel very lonely, I do not attribute this to my infection with Hepatitis C. I do not see my family as often as I would like. I do have friends but I have lost a lot of people over the years. A few years back I lost 7 friends in one year - my best friend and her husband; my mother; a school friend; a friend from church; a friend from work. Since then, someone else dies every year and my friendship circle has diminished significantly. Most of my closest friends who are still alive are married or have partners, so they have things to do. To talk to anyone I have to go to a club and meet people, and most of the people are older than me. Sometimes the phone doesn't ring, and there are days when the only person I speak to is the cashier in my local supermarket. Of course, living with the fear of Hepatitis C in the back of my mind, and worrying that I may get very ill in the future, makes all of this death and loss that much more difficult.

36. When I told my family that I had Hepatitis C, they were very surprised. My youngest daughter went straight to the GP and got tested for Hepatitis C. Thankfully she was all clear. My older daughter did not get tested. When I told them that I had contracted it during the sterilisation, they said it was good that I found out where it came from. I have had a conversation with them and told them where everything is if I conk out – I have all of my affairs in order.

37. I think that both of my daughters are happy as long as I am jogging along, because I am still healthy and well enough. We do not really talk about the Hepatitis C infection very much. My sister has been my main source of support – as I mentioned earlier she went to see Dr Bird with me for the first time.

38. My friends have taken my diagnosis with Hepatitis C on board, and I do not think that it has had an impact on my social life. I did not really want to make a big thing of it, but last year whenever I saw my friends they kept asking why I was being so particular about my diet. I wasn't drinking and they kept asking why, so eventually I just told them that I was looking after my liver. The friends I have told have been very concerned and supportive. One of my friends has cancer, so obviously I am more concerned for her, but she is still concerned for me. I have not come across anyone who has distanced themselves from me or not wanted to know me since my diagnosis.

39. I do not think that having Hepatitis C has made me less willing to go out. The only thing is that when I do go out, I am very conscious of my diet, which isn't always easy when you go to a pub and everything comes with chips! I guess it is a bit unfair that I can't have a drink anymore, but I was never a huge drinker so I do not think that this has had changed my social life. Since Samantha May explained how the virus spread, I also do not feel so worried about passing it on and rarely think about it. I mean, of course the virus is always there so it is

always in the back of my mind, but I do not think it has stopped me socialising with people.

40. Over the years I have experienced some hair loss and recently I have had achy joints. I am not sure if this could be influenced by the Hepatitis C, or just part of getting older. While I was still with my husband, there was a year that I was very unwell with dysentery and lost a stone in about 3 days. Again, I do not know if the Hepatitis C caused this.

41. I don't think that I have experienced fatigue or brain fog caused by Hepatitis C. Although I have felt more tired this year, I read that as you get older you cannot absorb your vitamins so well. I started taking Floradix (liquid iron), and this has helped massively with the tiredness, Other than that I have had the flu a few times, but not full blown influenza or anything out of the ordinary.

42. Although I was offered Harvoni, I decided that I did not want to take it. I have not had any difficulties accessing any treatment, nor do I believe that other treatments ought to have been made available to me. All of the treatments they offered had associated side effects, and as I am living alone I really do not want to risk having fatigue or other side effects.

43. I was raised using homeopathic medications and this is how I manage my infection. After being diagnosed, I went to a homeopath who took a holistic approach – she looked at every part of me for two hours as opposed to just looking at the illness in isolation. She prescribed me some medicine to help my immunity, a 'liver mix', something for my hair, something to protect me from cancer, and something for my heart. I also take milk thistle, cod liver oil and liquid iron. Although some people say that homeopathy doesn't work, I truly believe it does.

44. I can treat myself for cold, coughs and flus. I brought my liver enzyme levels (ALT levels) down from 49 to 36, and although the nurse said they could rise again, I want to fight the virus naturally. I hope that I can combat the Hepatitis C naturally; I believe the fact that I have had the virus for 40 years and it has not reared its ugly head shows that this is possible. I still go to see the specialist nurses every six months to monitor my liver and the virus.

45. I have not had anything go wrong yet when I have gone to the dentist or the opticians for treatment. The only thing I noticed was that they give you a form to fill out which asks if you have various illnesses or conditions. I selected no for everything until I got to the bottom of the form, where it asked if I had Hepatitis C. I ticked yes. Later, I asked Samantha May at the Hepatitis C Trust if declaring my illness in this way would make things difficult for me in the future. She told me that I did not actually have to disclose this information.

46. As I was diagnosed so recently, I have not encountered any stigma. The friends and the people who have treated me know it was out of my hands. I think that if I had HIV this attitude may be different, as I think there is a lot more stigma around HIV.

47. I was retired by the time I was diagnosed, so I have never had to declare my illness on a work related form or survey.

48. I am so angry that I got it because it does impact on your life. I am well at the moment, but who knows how long that will last? Other people have it much worse than me, and I feel angry for them too. I live with constant fear and anxiety because I have read other peoples stories and it is just horrendous and so awful. I just don't know how I would cope if I became really ill - I would either have to take the medication and hope for the best, or just get very unwell and die. The only silver lining is that now I know about it, I have been able to change my life for the better and fight it.

Section 6. Treatment/Care/Support

49. As aforementioned, I was offered Harvoni but decided not to accept treatment. I did not experience any difficulties obtaining care and support. I see the specialist nurses every six months for bloods tests and ultra sounds. I have the option to take the treatment if I change my mind.

50. No counselling or psychological support has ever been offered to me since my diagnosis. I think that when I was diagnosed, I was more in need of information than counselling, because I thought it was a death sentence. While I do not think that I personally need counselling, I do think that other people in my position would benefit from psychological support. If I had been offered counselling at the time of diagnosis, I probably would have accepted it.

Section 7. Financial Assistance

51. I have not had any financial assistance. The specialist nurses did mention that I could get compensation, and Samantha May at the Hepatitis C Trust sent me information and the forms. The forms said that I needed evidence. Since reading the forms I have not taken it any further or made an application because I feel guilty – there are so many people worse off than me.

Section 8. Other Issues

52. I would like clarity on whether I can still be an organ donor if I have Hepatitis C.

53. I heard on the radio that back in the 70's there was a kind of 'shop' (for want of a better term) in America where people were paid money to give blood. I think this is so alarming, and that surely the blood

purchaser for the NHS should have known about this and how dangerous it was. I don't know if the people on the ground – the doctors and nurses - would have known, but surely the people who bought it should have known where it came form.

54. I have never taken part in any litigious process in reference to my infection with Hepatitis C through blood transfusion, nor have I spoken to the press. I have not done any campaigning or spoken to an MP.

55. I do have my GP medical records. I tried to get my hospital records but they said that after 25 years it is likely that the maternity unit would have destroyed them. I have read my GP records and there is nothing in them that contradicts the version of events that I have provided in this statement. There is nothing in my medical notes that expressly states I contracted the Hepatitis C through a blood transfusion. Although, I cannot think of any other way that I could have been infected with this terrible virus.

Statement of Truth

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

Signed **GRO-B**

Dated 7th August 2019