Witness Name: GRO-B
Statement No: WITN1886001
Exhibits:WITN1886002–
WITN1886007
Dated: 3 September 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1. Introduction

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

Section 2. How Infected

2. I found out in 1977 that I was a carrier of haemophilia A. I had always bruised easily and had bled quite a bit following dental procedures, but in 1977 my eldest son had to have his tonsils out and was diagnosed with haemophilia A. I was then tested and found to be a carrier. Later my doctors told me that I should be treated as a mild haemophiliac.

3. I was not given any blood products until 1983 when I had a D&C procedure and later a hysterectomy. It was such a long time ago that now it feels to me that it all happened at the same time. I understand that my medical records indicate that the D&C procedure took place in February 1983 and the hysterectomy in September 1983.

4. The D&C procedure took place at GRO-B My records state that before the operation I was given Factor VIII. I was not aware that I had been given Factor VIII at all until my solicitors for the Inquiry obtained my medical records. I do not recall ever being told that I was given Factor VIIII for this operation or at a later date. I do not remember being told that there was any risk of me being exposed to an infection around the time of this operation.

5. After the procedure my doctors informed me that I had endometriosis and prescribed Danol. I took Danol for six weeks but stopped taking it because I began to feel nauseous. However even after I stopped taking it, I continued to feel nauseous and then developed jaundice, muscle cramps and abdominal pain. I felt horrible.

6. I went back to my GP and was admitted to hospital, according to my records this was in June 1983. I was told that I had hepatitis. I remember clearly that I was told that this reaction was probably caused by the Danol. My records show that my doctors thought at first that this was the cause of the hepatitis, however it was later decided that it was more likely that I had non A non B hepatitis caused by the use of Factor VIII. I exhibit the relevant letters from my records **[WITN1886002]**. I did not know that my doctors suspected at that time that I had non A non B hepatitis. I remember one of my doctors saying that I was such an unusual case that he might have to send a letter to the board. However, I believed that he was saying this in jest.

7. I was not ever informed that my hepatitis was caused by the factor VIII rather than the Danol. It was not until many years later that I discussed hepatitis again with my doctors.

8. I was admitted to GRO-B on 4 September 1983 for a total hysterectomy. The night before the operation I read a magazine article about AIDS being spread through blood products. I did not know what it all meant and asked the ward sister about it. I was interested to find out more, but I was not concerned as I had not made the link between the article and my own situation. The next thing I knew I had two consultants by my bed. They said to me something along the lines of "what is this you have read about AIDS" I told them about the article. They reassured me that I had nothing to worry about. I did not mean anything to me at the time, I just thought that it did not apply to me.

9. The operation took place on 6 September 1984. I understand from my medical records that I was given factor VIII before the operation. I do not recall being told that I was given Factor VIIII for this operation. I was not informed that there was a chance that I would need a blood transfusion, I was not told before or after the transfusions that there was any risk of infection.

10. After the operation they kept taking me down to theatre because I was haemorrhaging. I was given three units of blood but I continued to bleed. Around 9 or 10 days after the operation they put padding inside me and according to my records I was given factor VIII and another 8 units of blood. However I had another haemorrhage a few days later and was given more padding and more blood.

11. I was rushed to GRO-B on 20 September 1983. Over the days that followed I was given bags and bags of blood and bottle after bottle of Factor VIII. I do not know exactly how much Factor VIII I was given however my medical records include a note which states "*to have 6 bottles Factor VIII*

12hrly for 3 days". In the last few days of the admission I was switched to Cryoprecipitate. Eventually the bleeding stopped and I was transferred back to GRO-B on 17 October 1983. I was finally discharged home on 20 October. I had felt so terrible after the last procedure and was worried that I would develop jaundice again. I understand however that my liver function tests were normal.

12. My medical records include a card listing the batch numbers for some of the units of blood I received at GRO-B [WITN1886003] and at GRO-B GRO-B [WITN1886004].

13. Over the months that followed I built up my strength and eventually recovered from the operation. I don't think I ever really felt back to normal but because I was a mum I just got on with things. I did not put together the article that I had read and the blood products that I had received.

14. One day in September 1985 I had a check-up at my GP surgery. In those days we had a family doctor. He mentioned my son GRO-B and said that as he was coming up to 16 years old, he would soon start to be interested in having a girlfriend. He asked me whether I thought it might be a good idea for GRO-B to have a blood test to make sure that he was ok. The doctor said that as I had been given so much blood after my hysterectomy then I should have a blood test too. I asked him what for, he said for AIDS. It sounds so odd now but at the time I just went with it, it seemed to me that the doctor was saying that we were better safe than sorry. So I agreed and blindly made the appointment for me and GRO-B to be tested at GRO-B

15. I understand that there is a letter in my medical records from our family GP to GRO-B at GRO-B referring us for an appointment at her clinic. The letter refers to GRO-B being a haemophiliac and to me having received Factor VIII in 1983. It goes on to say that "*I hardly need tell you the reason for my letter. A.I.D.S. is a worry and the recent circular which we received, whilst*

giving excellent guidance to the undertaker, really gave no guidance to the management of this type of problem." The final sentences of the paragraph are redacted. This redaction was made before my solicitors received these records **[WITN1886005]**.

16. GRO-B and I went to the clinic at GRO-B and had the test. We had to had to wait three months for the results. We went to get the results together, GRO-B was at college that day. He was only 15 at the time, he believed that if the results were positive that he would never get a partner and so he asked me whether we could get a dog to keep him company. When we got to that room the doctor said to us "there is good news and bad news. The good news is that GRO-B you are OK and the bad news is that GRO-B you are not."

17. I believe that the results of the tests were communicated very badly to us. I went home thinking: I am glad it is me and not GRO-B. I did not know much about HIV at that time, I had seen the tombstone adverts on the telly but apart from that I did not know anything.

18. I think that I had another appointment soon afterwards. I was told that the infection could be passed by blood to blood contact and sexually. I was told to be aware that if I cut myself the blood would be contaminated. I wasn't given any information about what treatment was available and what it would be like to live with HIV. I wasn't really given adequate information to understand the infection. However GRO-B s specialist nurse came to my house to chat things through with me, she was really helpful and answered lots of my questions.

19. From what I remember the doctors said that they would send me information. They also said that medicine is a fabulous thing and in 6 months you will be fine. I thought to myself that I would just take each day as it came.

20. In around 2005 a new consultant, GRO-B took over my care at GRO-B GRO-B At my first appointment with her she said something along the lines of

"oh I see you have had contact with Hepatitis C." This was the first that I had heard of hepatitis C. GRO-B said that I did not need any treatment at that time and she just left it at that.

21. Around the time that the Infected Blood Inquiry was announced a consultant at GRO-B GRO-B phoned me up. He said that he could see from my records that I had previously been exposed to hepatitis C and that he was worried that I had slipped through the net. I went in to see him and he took lots of blood to be tested. I haven't heard anything since then. I am sure he would have contacted me if there was anything to worry about.

Section 3. Other Infections

22. I have received a letter stating that there is a possibility that I was in contact with vCJD. I do not believe that I have any other infections passed through contaminated blood, at least I have not been tested for any other infections.

Section 4. Consent

23. I think that within medical circles they knew of the risks. Looking back I do think it is odd that all of a sudden I had the haematologist and two other consultants by my bed as soon as I mentioned that I had read an article about AIDS. I can't help but think that they knew about the source of the blood and that they were gathering data.

24. In relation to the Hepatitis C, I only found out by chance when a new consultant had reviewed my notes and just assumed that I already knew. I did not give my consent to be tested, I was not aware that I had been tested.

Section 5. Impact

25. For the first few years I did not feel too bad physically. However psychologically it turned my brain inside out, it was absolutely traumatic, it really was. I was just trying to lead a normal life, I did not want to know or think about it.

26. Sometimes I felt physically unwell, I was exhausted, lethargic, sick. I knew that I had to keep myself fit physically, there was one time that I thought I would give up and that I did not want to drag it out. A couple of times I was quite poorly. I had pneumonia in 1997 and was admitted to hospital, I developed a pleural effusion and nearly died. At times the medication and taking all of the different tablets together turned me inside out.

27. In the first few years after I was diagnosed I was informed that I did not need to take any medication because I was asymptomatic. In around 1992 I was told of a trial that I could be considered for, this involved taking a new drug, Zidovudine. However I was later informed that this medication was not as effective as had first been thought and so it was not available to me. I didn't mind because I didn't want to take medication anyway, I was of the view that if I could get on with my life without taking medication I should do.

28. However in 1993 it was decided that I should start taking medication. They told me that it would be beneficial to me and so I agreed. I was first prescribed prophylactic fluconazole and pneumocystis prophylaxis. In August 1997 I was informed that I would need to start taking antiretroviral treatment and was prescribed Combivir. I believe that this was effective at first and I took it for a few years. However then they decided that they would change it and the new medications really did not agree with me. This was when I was receiving treatment at GRO-B I was so jaundiced and could not move my joints. I told the HIV nurse that I was really worried. After that I was transferred back to GRO-B the consultant at GRO-B

29. GRO-B reassured me, it was his field to make sure that all of the medications were right. He was trying out new medications that he said only certain hospitals could access, it seems to be a postcode lottery in terms of the medication that is available.

30. I did not feel that I had continuity in the early days. Continuity means a lot, otherwise you have to say the same story over and over again. My current doctor, GRO-B, has been fantastic, when she first heard that my husband was poorly she agreed to arrange for my medication to be delivered by post so that I would not have to go over to GRO-B I still see her for check-ups every six months, I have to have tests and the results come roughly three weeks later GRO-B says to me that if there is something wrong she will ask me in for an appointment, if there is nothing wrong she will just see me in six months. I don't see the point in taking up everyone's time by going to an appointment to be told that nothing has changed.

31. I do not know of any other treatments that could have been made available to me. I left it to the professionals.

32. I think that the biggest impact on me was mentally. I used to have flashbacks of the diagnosis appointment and of the operation. I felt that the stress of everything was above my head the whole time. The stress of trying to keep body and soul together as well as my family. That has had a big impact.

33. When I was diagnosed I was working as a hairdresser and was very sociable. However, I felt that the only way I could cope with the diagnosis was by not talking about it, I told only a handful of people. I told my husband straight away. If GRO-B had not been with me when I found out I would not have told him, at least not at that time. But because GRO-B knew we had to tell his sister who was a year older than him. We told them both not to tell anyone. We all knew it was there but we never talked about it. We were coping and this is the way we

decided to do it. When you have made a promise not to talk about something, you just get on with it and do what you need to do.

34. GRO-B if you go anywhere you will see someone that you know. There is always somebody who knows somebody else. There was scaremongering on the television, radio, and in the newspapers at that time. We are such an open family usually but living GRO-B in a very tight community made me feel that this issue had to be a secret. I did not want to hurt my family and particularly the children who were still at school when I was diagnosed.

35. My husband was in the police force and I was worried about what might happen if people knew that his wife had HIV, in those days it would have affected his work. I was worried about the stigma of it. The most important thing to me was protecting my family, I thought that I was doing this by keeping it all a secret. I felt that if I opened up about it that I and the rest of the family would have been alienated.

36. My youngest son is now in his forties. He was only 8 years old when I was diagnosed. When he was 15 he was told about my diagnosis in an unexpected way. We had booked a family holiday to the United States and I had to declare that I had HIV for the purposes of the visa. My husband was worried that our son would somehow find out at the airport and so he took him up on the downs and told him that I had HIV. My son changed from that moment on.

37. My son has been in hospital three times as a result of attempting suicide; luckily we are a solid family, and we have always been there for him. It was only recently that he told me that it was finding out about my diagnosis that started all of his problems. He did not want to talk about it at the time, he went into his shell because he thought that he was going to lose his mum.

38. I did an awful thing that I now always feel guilty about. When my eldest son got engaged I pleaded with him not to tell his finance about my diagnosis. My daughter got engaged soon afterwards and I asked her the same thing. They both agreed. They were married within four months of each other. I feel dreadful now about asking them to do this for me because you should not keep things from your partner, but at the time I felt that I was doing the right thing.

39. When my son's wife told me that she was pregnant I felt that I had to say something to her. She came up to see me and I told her about the HIV. I said that if she did not want me to have anything to do with the baby I would be devastated but I would understand. I was terrified about how she would react but she was fantastic, she said of course she wanted me to be involved.

40. My grandchildren are adults now but I have not told them. I never really gave them big kisses, we always gave each other air kisses and still do now. My grandchildren are in their twenties and none of them know, it is one great big horrible secret. With everything that has happened my attitude has changed greatly, I wonder whether now might be the right time to tell them.

41. When I was diagnosed my social life closed down for a while, I pushed everyone away. I just tried to get on with things but sometimes the issue of infected blood would come up and I would freeze and think that everyone was staring at me. Especially when they knew that my son is a haemophiliac and that I am a carrier. The only people I told outside of my immediate family were just one of my friends and my niece. I did not ever tell my two brothers because I just didn't want to upset them.

42. I felt that I had to stop hairdressing after I was diagnosed because it involved using scissors and razors. I used to do a couple of little old ladies but that was it. I was devastated. I was used to chatting to people and being an open book. I became quiet and quite withdrawn. I had been very outgoing but I found it so difficult not sharing what I was going through. It's very hard when you are quite

outward and used to talking, I had to become a good actress. Someone asked me once if I had read about haemophiliacs being infected with HIV through blood. I didn't know what to say.

43. I felt isolated and I lost my confidence. I would go and look in the windows of shops and think that there was not much point me looking because I wasn't going to be around for much longer.

44. My husband was very good and very supportive. He was a policeman one minute and a family man the next. But the whole thing was very hard on him, he did not make an issue of any of it but I know that underneath he felt awful. In November 2015 my husband was diagnosed with pancreatic cancer, he died four months later. I was diagnosed with colon cancer 16 weeks after that and was on chemotherapy for 8 months. I think the stress of everything played a part in me developing cancer.

45. At GRO-B they would often ask me if students could observe appointments, I always felt that they were looking at me thinking that I was dirty. Whenever I am in hospital for anything I feel that all of the staff are aware that I have HIV, there are yellow stickers on everything.

46. I was always brought up to respect professionals but these experiences make you question everything. Now I always ask why do you need that, or why are you doing that?

Section 6

47. My infected status has meant that I have had to travel to GRO-B for dental treatment that I could have had closer to home. However this is my choice because I did not want to go to the local dentists. I know that they have a duty in relation to confidentiality, but I have known receptionists that are not supposed to say anything but do.

48. I have not been offered counselling for anything related to HIV or Hepatitis C. I don't think this would have been of benefit in the early days. I didn't want to talk about it, I basically just didn't want to know.

Section 7

49. I first found out that there was financial assistance available through my son. I was part of the HIV litigation and first received payments from the MacFarlene Trust. I received a one off payment of £60,000 when I applied. When I was first in touch with them they sent me a long list of things that I could be helped with including driving lessons, it seemed that financially they would be able to help and you just had to ask. I applied for a fridge and a boiler and received the funding for these.

50. I now receive payments from EIBSS, they have recently increased my monthly payments. My husband used to complete all of the official forms and things and so he did most of the application for me. I don't think we had any difficulties. I remember GRO-B nurse told me that we had to get it in by a particular date. At first, I did not want to apply but my husband said that they owed us and we decided to do it.

Section 8

51. As mentioned above I was involved in the HIV litigation which resulted in the payments from the MacFarlene Trust. As part of this litigation, consultant haematologist GRO-B wrote to GRO-B Health Authority setting out the dates that I received Factor VIII treatment. The letter makes several comments which I believe may be on interest to the Inquiry. I exhibit the letter to this statement **[WITN1886006]** however I will set out a few of the comments here:

- *I feel that Cryoprecipitate or DDAVP could have been used to treat her instead of factor VIII concentrate*
- *As far as I am aware she was only given NHS factor VIII Concentrate (non heat treated)* GRO-B
- *As far as I am aware she did not have commercial Factor VIII Concentrate* GRO-B GRO-B
- *In 1983 the clinicians looking after this patient were almost certainly not aware of risk of transmitting HIV by factor VIII concentrate and therefore failed to inform the plaintiff of the risk (though looking through the notes the patients seems to have been aware of this risk)*

52. I am not sure what is meant by this last point. It could be referring to the conversation that I had with the doctors before the operation about the article that I read. However the medical records provided to my solicitors from GRO-B GRO-B do not include the notes of my operation on 6 September 1983 or the days immediately before and afterwards.

53. Included in my GP records is a letter from the Medicines & Healthcare Products Regulatory Agency dated 16 March 2016 **[WITN1886007]**. This letter requests information for a study into haemophilia. It seems to suggest that the GP will receive £55 per patient for information about them. I was not aware of this letter before my solicitors brought it to my attention. I do not know whether my GP ever replied to this request for information however I thought it may be helpful for the Inquiry to see this document.

Statement of Truth

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

Signed GRO-B

Dated 3.9.20.