Witness Name: GRO-B

Statement No.: WITN0850001

Exhibits: WITN0850002 – WITN0850005

Dated: 14th October 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

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

Section 1: Introduction

1. My name is GRO-B. My date of birth is GRO-B 1957 and my address is GRO-B GRO-B I have worked for over 40 years as a nurse. I took early retirement in 2014. I now work part-time as a chronic pain nurse in GRO-B

2. I carried out my enrolled training in Glasgow, and worked as an enrolled nurse on a medical ward. I then did my registered nurse training in GRO-B from 1978 to 1981. After my training, I moved to London and worked on an intensive care unit, before moving back to GRO-B and then to GRO-B

3. In 1989, I met my now husband, GRO-B and we married in 1991. We have no children, but have enjoyed a nice life and we are happy.

4. In 1996, I moved to GRO-B with my husband, GRO-B as he got a new job. I was first involved in the recovery department and then in research. I then developed an interest in acute pain.

5. I make this statement about the impact of my Hepatitis C infection. This statement is based on my recollection of events, as I have not yet received a copy of my medical records.

Section 2: How infected

Haemophilia

6. I was diagnosed with Von Willebrand disease in 1983 at the age of 26 in GRO-B It took a long time to get this diagnosis, and I suffered for a number of years with heavy nose bleeds, periods and bruising. My mother was a nurse and always suspected something was not quite right, but we were not sure what I was suffering from.

7. I got my period in 1970 at the age of 13, and had to go to the GRO-B Hospital because the bleeding and pain was so severe. The doctors thought I was pregnant and I was treated very badly. My haemoglobin was low, so I was given blood products and an iron infusion.

8. Following this incident, I was tested for lots of different blood disorders. At first, the doctors thought it was because I had low vitamin K levels, and I took vitamin K three times a week. I was told in the event of a severe bleed I would require plasma rich protein infusions. This was something I do not think I was ever given.

9. In 1979, I had my wisdom teeth removed at the Aberdeen Royal Infirmary ("ARI"). After the surgery, I was told I had bled a lot. When I came round my face was very swollen and I had difficulty breathing as I had a Brighton balloon in situ. I am aware that I was given a blood transfusion at this time.

10. Nothing was said then about the exact amount of bleeding I had suffered during the operation, but the anaesthetist and other doctors kept a close eye on me following the procedure.

11. In 1981, I had a small breast lump removed. Due to the issues with excessive bleeding that had been experienced during previous surgeries, I was given some form of preventative treatment. I am not sure what this was, but I think I was given Factor VIII product. This was the first time I would have received Factor VIII.

12. I was also given Factor VIII during a visit to my GRO-B in Edinburgh in December 1982. My GRO-B had taken me to the Accident and Emergency department at the Edinburgh Royal Infirmary, as my gums were oozing with blood, which I was swallowing. This was the second occasion I received Factor VIII.

13. I do not recall any information or advice provided about the risk of being exposed to infection from blood products. However, I think it is unlikely that I was told of any risks, as I would have questioned whether there were any alternative treatments available, which is what I did later, after I was diagnosed with Hepatitis C.

14. In 1983, I was moving to London and was given a letter by Dr Audrey Dawson, Consultant Haematologist, to hand to my General Practitioner in London to let them know I had Von Willebrand disease and that if I required surgery or dental extraction I would require Factor VIII cover. When I handed this to the GP in London, she sent me to a haematologist, Dr Tuddenhem. I believe Dr Tuddenhem worked at the Royal Free Hospital. Dr Tuddenhem was initially not convinced I had a bleeding disorder, but diagnosed me with Von Willebrand disease in 1984 after a number of tests. He said it was an unusual type, Type 2A, which made it initially difficult to diagnose. This was the first time I had received an official diagnosis.

15. Following my diagnosis, my family were also tested for haemophilia. We discovered that my father had had Von Willebrand disease. I recall him saying that he had bled when he had some teeth out when he was younger, but I do not

think he ever received any blood products. Both of my siblings, a brother and a sister, did not have or carry a bleeding disorder.

16. I lived in London until 1985 and was registered with the main Haemophilia Centre in Oxford. During my time living in London, I did not receive any blood products.

17. I have always suffered from extremely heavy periods. I visited a gynaecologist a few times for this, but they could not see an issue. I was given intranasal Desmopressin ("DDAVP"), a synthetic blood product, in 1998 for this, but I was not convinced that this helped reduce the bleeding.

Hepatitis C

18. I do not know how I was infected or when I was tested for Hepatitis C. As far as I am aware, I only received Factor VIII products on two occasions. I moved back to GRO-B in 1992 from GRO-B and was told in 1993 at the ARI that I had Hepatitis C. At the time, I was also working as a nurse at the ARI.

19. I remember being called in for an appointment at the ARI as I was told that the doctor wanted to see me. I do not think I had routine appointments for my haemophilia back then. I saw a doctor in haematology who told me I had contracted Hepatitis C, and I recall him saying that they had been looking for me. I thought this was an odd phrase to use, but I assume it was because I had been tested at the ARI a number of years previously, unbeknown to me, and I had then moved out of the area, to GRO-B

20. As soon as I was told I was infected with Hepatitis C, I refused to be treated with any further blood products. I asked for alternative synthetic products to be used instead.

21. I was not given much support when I was first diagnosed. I was given no information about Hepatitis C. I was given a leaflet by a close friend and work

colleague after I had told her about my diagnosis. I had to seek out information, rather than this being provided to me. I would make enquiries with colleagues about how it could be transmitted under the pretence that I was asking in relation to the treatment of a patient.

22. In 1996, just before I moved to GRO-B, a Hepatitis C clinic was started at the ARI. This was the first contact I had with the medical professionals since the diagnosis. I was informed that doctors would be present at the clinic on 4 March 1996 to advise me, and so I went to the clinic. One of the doctors who was present was a Consultant Physician I was previously a ward sister with. I hid around the corner, embarrassed to be seen. I had blood taken by a different doctor and then left. I recall that they later stated that they had lost the blood samples taken, by which time I was in GRO-B.

23. When I moved to GRO-B in 1996, I registered at the Haemophilia Centre in Newcastle and told the doctor there that I had been diagnosed with Hepatitis C at the ARI. Further tests were carried out by Dr Peter Jones in Newcastle and I was told I had cleared the virus on 8 July 1996 [WITN0850002]. The viral tests came back all clear, except for the preliminary testing.

24. I do not know if the tests were different in Newcastle, but a possible explanation is a change in the method of testing. My view is that the Haemophilia Centre in Newcastle was more organised than at the ARI, and I am happy with the contact I had with the centre. I exhibit [WITN0850003] a letter from Dr Hanley, Consultant Haematologist to Peter Stevens at the Skipton Fund, dated 26 November 2004, which was sent to me which outlines the development in tests. It states *"the major reason for this is due to the history of the way tests for HCV were developed. For many years it was not clear that some individuals, like* GRO-B *did not actually have chronic HCV infection. It was only with the availability of sensitive PCR testing as well as an increase in knowledge of the natural history of HCV, that ultimately reassurances could be provided. Over the years prior to this, patients*

were living with much uncertainty and many suffered considerable trauma as a result." It is not certain how I cleared the Hepatitis C virus, but I did so naturally.

25. I remember attending the appointment the day that I was told I had cleared the virus. It was a huge relief. I was applying for jobs in GRO-B at the time and knew I would not be employed if I had to declare the infection.

26. I have not received any blood products since living in GRO-B and, to date, remain clear of Hepatitis C.

Section 3: Other infections

27. I was tested for HIV in GRO-B in around 1988 and I received some counselling beforehand, but this was through work as there was a patient in the intensive care unit who had HIV. The counselling was offered by the ARI. I am not aware of whether I was ever tested for HIV as a result of the blood products I have been given.

28. I am not aware of any other infection that I have received as a result of being given infected blood products. I have recently been diagnosed with Graves' disease and Sjögren's Syndrome, which are both autoimmune diseases. My symptoms include dry eyes, dry mouth and a burning tongue, but I am not sure whether these autoimmune conditions are related to receiving infected blood products.

Section 4: Consent

29. I was not aware at the time that I had been tested for Hepatitis C and I am still not aware of when I was tested. I do not know if I was tested for HIV too, due to a concern about the blood products I received, or tested for any other infections.

30. My husband was not offered any testing for Hepatitis C. With hindsight, we should have sought this out.

31. The first time I received blood products was at the age of 13. I was not asked for consent to receive it, although my mother may have been involved. I do not recall being asked to give my consent when being given blood products at the ARI or Edinburgh Royal Infirmary, but I recognise that the instance in Aberdeen was during an emergency, as previously described.

Section 5: Impact

Psychological impact on me

32. The Hepatitis C virus has had an impact on me psychologically, particularly as I was in the medical profession. It was difficult to be told that I had Hepatitis C and continue to work in a hospital. When I was first diagnosed by the ARI, I was told by the doctor at the time to keep it a secret. I believe it has contributed greatly to my ongoing anxiety issues.

33. I hid my diagnosis from close friends and work colleagues. My family knew about the infection, but we did not discuss it. Whether this was my fault I do not know, but I did not want to talk about it.

34. It was a big thing for me, to see a Hepatitis C label across on my medical notes. I was constantly worried someone at work would find out. I wondered what would happen if I needed an operation, and I had made a plan to travel to a hospital in Dundee if I ever needed treatment, rather than risk being treated at the ARI.

35. I was never comfortable with keeping the diagnosis a secret, but the doctor said it would be okay and I was not told to declare it. Instead, I was told not to think about it. It was only after I had some time to digest the diagnosis that I went back to the consultants at the ARI for a second appointment and was angry with them.

36. When I was told that I had contracted Hepatitis C, initially I was in shock. I did not understand how it had happened and I felt lost. I wondered where I could get more information and I was worried about working because at that time I was working in theatre. I was overly careful with all patients; thoroughly washing my hands and wearing gloves.

Physical impact on me

37. I did not notice any immediately obvious physical symptoms as a result of being infected with Hepatitis C, but have often wondered whether my autoimmune diseases are linked to it. I did not have to take any time off work as a result of being unwell because of the Hepatitis C infection.

Impact on private, family and social life

38. As I did not tell my friends about the diagnosis, with the exception of a close friend from work, my social life continued as before. It was an unspoken thing, and it has been difficult to explain to our friends why we did not have children.

39. At the time of my diagnosis, my husband was studying to be a physiotherapist and it was a very pressurised time. We were newly married and had started talking about having children, but my diagnosis meant children were no longer an option. It was, and still is, very upsetting for us both, but thankfully we have dealt with it together.

40. A few years ago, just after I was told I had cleared the Hepatitis C virus, my husband became very ill. Before being diagnosed with an autoimmune muscle condition, he was tested for infections such as HIV. This was a very stressful and upsetting time, and I worried that I had somehow managed to pass an infection on to him. It felt like one thing after another.

Stigma

41. Although I only told close family and one friend so did not experience stigma, I felt that I would experience stigma if everyone knew that I had Hepatitis C. In those days, the word "*dirty*" was used to describe those infected in the hospital environment.

Impact on education and finances

42. I was diagnosed with Hepatitis C at the age of 36, and as such had completed my studies at that time. It did not have an impact on my education.

43. As I have been able to continue working and naturally cleared the Hepatitis C virus, which meant I was able to get a job when I moved to GRO-B, there have been no impact on my finances as a result of the infection.

Section 6: Treatment/Care/Support

44. I have not experienced any difficulties in obtaining treatment, but I did not tell anyone, such as the dentist, about having Hepatitis C. I realise that this was wrong, and I believe that I would have told the dentist had I required any treatment, rather than routine check ups.

45. In terms of stigma experienced when seeking treatment, there was one occasion where I went to an appointment with Dr GRO-D at the Royal Victoria Infirmary. I mentioned to the doctor that I had Hepatitis C in the past but it had naturally cleared, and I was shocked by his reaction. He was very rude and told me not to be stupid; that Hepatitis C could not clear and I would always be infected. I had been warned before going to the appointment about this specific doctor's lack of people skills, but I was upset by his reaction and put in a complaint. He did not act in a way that would be expected of a medical professional. I went back to the Newcastle Haemophilia Centre after this

appointment to query whether I still had Hepatitis C, and I was told that everything was fine. Over the years, I have received confusing information like this.

46. I have not been offered any counselling or psychological support from the doctors in relation to the Hepatitis C infection. Had I been offered this at the time, I do not know if I would have accepted it, as I was so concerned about people finding out about the infection. I have received some counselling from a psychosexual therapist in relation to my heavy periods, stemming from the Von Willebrand disease.

47. When I moved to GRO-B, I joined The Haemophilia Society and explained my situation. They were helpful and gave me support.

48. I am a very private person and it is difficult to open up. I am good at giving advice, but not as good at taking it.

Section 7: Financial Assistance

49. I have never received financial assistance in relation to the Hepatitis C infection I contracted through contaminated blood products. Fortunately, though, I have always been well enough to work.

50. In 2004, the head of the Haemophilia Centre in Newcastle, Dr John Hanley, applied on my behalf for compensation from the Skipton Fund because of the worry that I had been through as a result of contracting Hepatitis C. It was through this application process that I learnt that Dr Hanley felt quite strongly that I had been infected at the ARI, rather than in Edinburgh.

51. As I had naturally cleared the Hepatitis C, I was told that I was not entitled to any money from the Skipton Fund, but could apply if I developed Hepatitis C again. I did not wish to pursue an appeal against this decision. I exhibit a copy of the letter

received from the Skipton Fund dated 18 November 2004, explaining their rationale for this decision [WITN0850004]. The Skipton Fund also wrote to Dr Hanley on 18 November 2004 in response to the persuasive letter he wrote to accompany my application [WITN0850005]. The letter confirms *"the reason for this delay is that we have been arguing strenuously with the DoH officials that the exclusion from this scheme of this small group of individuals was not just mean-minded but also... unfair.... I am very sorry to have to do this, since your letter is perfectly persuasive for me. We are, however, operating only as agents for the DoH, and while there are cases in which we can exercise discretion in the interpretation of scanty or ambiguous evidence, in this area there is no room for such discretion and we must do as we are told."*

Section 8: Other Issues

52. I feel very grateful that Hepatitis C has not had a greater impact on me. I have had a great career and a good life, and as a result of the Inquiry have heard stories which have made me realise how fortunate I am.

53. I am hoping that the Inquiry provides me with an opportunity to talk about my Hepatitis C infection and allows others to talk about the infections they may have had as a result of being given infected blood products. I was not involved in the Archer Inquiry and have not previously had the opportunity to speak about the impact of my infection. I would like to get it out in the open and air my thoughts on the impact it has had.

54. Recently, the Inquiry was mentioned on the television and a colleague questioned how people could have been given infected blood. I did not say anything about my infection, but I am hoping that the Inquiry educates those who have not had the same involvement as I have had.

55. It would be good to see those who were in authority being held accountable for their actions.

Statement of Truth

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

Signed ...GRO-B...........

Dated......14/10/19..............................