Witness Name: GRO-B
Statement No: WITN0428001
Exhibits: WITN0428002-9
Dated: September 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B I was born on the GRO-B of GRO-B 1959. My address is GRO-B. I live on my own. I have three adult children.

2. I stopped work several years ago for medical reasons. I suffer from a number of medical conditions. In the past, I have worked in factories.

3. I was infected with Hepatitis C Virus as a result of receiving contaminated blood products (Factor VIII Concentrate) in the 1980s. I have cleared Hepatitis C.

4. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are referred to in this statement.

Section 2. How infected

5. I have Haemophilia type A, categorised as mild.

6. Around 1964 or 1965, when I was 5 or 6 years old I had my tonsils taken out. I was in Wythenshawe Hospital Manchester (WHM) for 6 weeks. I nearly died and had to be taken back to theatre for more surgery. I received two blood transfusions during this period of time. At the time, I do not believe there was any mention of the fact that I was a Haemophiliac. My mother told me that the hospital said that my blood was not clotting quickly enough. She did not know then that my condition had a name, that I had haemophilia.

7. According to my medical records, I was treated with Plesmits in 1965, which I understand are a blood clotting coagulant. I have exhibited to this statement marked WITN0428002 copy letters from WHM dated 1965 and 1968 which relate to treatment I received at the time.

8. I was first told of my haemophilia A diagnosis in 1976. I was 17 years old and working in a rubber factory. My face began to swell and my manager told me to go to hospital. I went to the Manchester Royal Infirmary Hospital (MRI) where they told me I was a Haemophiliac. When I returned and explained my diagnosis to my manager he went to the Union representative and told them to get rid of me. I didn't receive any treatment at this time for my swollen face. I have exhibited to this marked WITN0428003 a letter from MRI dated 30 July 1976 confirming my FVIII deficiency. I do not have the second page of that letter.

9. Also in 1976, I had 9 teeth extracted at the MRI, under anaesthesia. I believe I may have received Factor VIII Concentrate (FVIII) during that procedure. I have NOT RELEVANT a referral letter from my doctor to the MRI dated 24 August 1976 which states that I am hemophiliac and requesting that I be seen in the dental clinic of the MRI for tooth extraction.

10. I had a tooth extracted in 1979. I may have been treated with FVIII on this occasion but I do not recall the details of my treatment.

11. I did not receive FVIII often. I only received it if I had an injury or needed surgical treatment. I always had it at the hospital and never at home.

12. I remember an occasion in 1987 when I was treated with FVIII. It was New Year's Day and I lost the use of one of my arms. My father took me to the Manchester Royal Infirmary (MRI) as I was panicking. When I arrived at the hospital the doctor told me to come back if my arm was no better in 3 days. I returned to the hospital after 3 days because my arm had by now swollen. The hospital put me on a course of FVIII to treat my arm. I went to the hospital every day of the week for a month to receive my treatment. After this I had heat treatment and physiotherapy to regain the use of my arm.

13. In 1989, I sustained an injury to my arm for which I was treated with FVIII at the MRI. I had been doing some light exercise and my arm began to swell due to internal bleeding. I saw the haematologist at MRI and he administered the FVIII treatment. As far as I remember I received treatment for one or two days. All treatments would have been at the hospital.

14. In 1989 I also had some teeth taken out. I would have been treated with FVIII but I cannot recall precise details.

15. All of my treatments took place at MRI. My Haematology consultant in 1976 was Dr H McIntyre. In later years I was under the care of Meg Bolton, then Dr Hay. On one occasion when I took my friend to an appointment at the MRI there was a purple file on the GRO-D desk. He seemed concerned that I had taken a stranger to my appointment and seemed a little panicky about the content of the purple file. At one stage when he left the room he told his assistant to keep a close eye on it. Whilst I have received copies of my medical notes and records I do not believe that I have received copies of that purple file and I wonder to this day what it contains.

16. I was never warned of any risks in relation to blood products. I never knew. I wouldn't have allowed FVIII treatment if I had known about the risks.

17. I was infected with Hepatitis C as a result of receiving contaminated blood.

18. I was told that I had Hepatitis C by letter. I am unsure as to exactly when this was but believe it would have been in the mid to late 1990s. I didn't know I was being tested for Hepatitis C so it came as a complete shock. I felt distraught when I received the letter.

19. The letter I received stated I had Hepatitis C and that was it. I wasn't told anything about Hepatitis C and I wasn't told to come in and talk to anyone after receiving the letter. I had no idea what Hepatitis C even was. I wasn't given any information, I got told nothing.

20. I have exhibited to this marked WITN0428004 copies of 7 letters written by Meg Bolton to GP dated 15 July 1997 to 24 March 1998. The letters state I was told that I was at risk for Hepatitis C in July 1997 and that I was informed of my infection in August 1997. As I stated above, the first I knew of my Hepatitis C infection was when I received a letter through the post, not at an appointment with my Haematologist.

21. I did end up seeing Meg Bolton and she told me that I was to be treated with Interferon. I was put on Alpha Interferon in November 1997 for 12 months. I refer to the letters contained in Exhibit WITN0428004 which document my treatment.

22. It was very difficult for me to get any information from the medical professionals. I started learning about my condition and doing my own research. I discovered that Hepatitis C can be transmitted. I have not been with a woman since finding out about my Hepatitis C infection. After I found out that it could be transmitted I decided no one was going to catch Hepatitis C from me. If I had known about my Hepatitis C infection earlier I would not have gotten married.

23. During my first treatment for Hepatitis C, my consultant at MRI changed to Dr Hay. Dr Hay continued with my Interferon treatment.

24. Initially, I was told that the treatment had worked. Unfortunately, however, in March 2000 I tested positive again for Hepatitis C. I have exhibited to this marked WITN0428005 a letter dated 16 February 2000.

25. I remember seeing Dr Hay and being upset and asking for treatment for Hepatitis C. Dr Hay had to fight to get me treatment for Hepatitis C due to funding.

26. I started treatment for Hepatitis C again on 7th Feb 2001. This time I was treated with Pegylated Interferon with Ribavirin for a period of 12 months. The treatment was successful and since that time Hepatitis C has remained undetectable. My last test was in February 2019.

27. I have exhibited to this statement marked WITN0428006 various letters from the MRI dated 8 May 2000 to 30 January 2003 relating to my second treatment for Hepatitis C.

Section 3. Other Infections

28. I do not know if I have been infected with any other infections other than those already mentioned.

29. I feel it may be a possibility that I have other infections that I have not been told about.

Section 4. Consent

30. I believe I was tested without my knowledge. I didn't know I was being tested for Hepatitis C as I was never told.

31. The hospital regularly took blood off me but to this day, from 17 years of age to 60, I don't know anything about my blood tests – I am never given the results.

32. As I didn't know I was being tested for Hepatitis C I was never given the opportunity to consent.

33. I do not know if I was tested for the purposes of research.

Section 5. Impact of the Infection

34. I suffer from many medical issues – heart disease, hypertension, iron deficiency, type 2 diabetes (insulin dependent), asthma, hearing loss, memory problems. I believe that my medical issues have been caused or made worse by my Hepatitis C infection. Every 3 months I have a B12 injection. I also attend a specialist podiatrist with regard to my legs and feet as I have been warned about the possible future need for amputation.

35. As a result of my Hepatitis C infection I have cirrhosis of the liver and scarring which I have been told could cause cancer. I have exhibited to this statement marked WITN0428007 a letter dated 1 August 2019 and an imaging report dated 31 July 2019 which confirm cirrhosis of the liver.

36. I have suffered from ill health for much of my adult life. Looking at all my medical notes has jolted my memory about the things I have gone through. I knew I was suffering but I never knew why. I never knew that being treated with FVIII would make me so ill, I was never told about the risks.

37. My mental health has really suffered as a result of my Hepatitis C infection and treatment. Finding out that I had Hepatitis C led to me isolating myself. I was an outgoing person before I was diagnosed. There was a lot of stigma surrounding Hepatitis C and HIV at the time and I was very aware of this. I felt guilty forming a relationship and so I gave up on relationships. I snapped. I was gone.

38. I suffer from memory loss. This has made me to lose confidence as I forget so many things and end up anxious and confused. My memory loss is yet to be investigated by the hospital but I wonder whether it is related to the Hepatitis C infection. I believe that Hepatitis C and the medications I received to treat it may have caused the problems I have with my memory. I find I cannot communicate in conversation with more than one person. I feel my brain has been adjusted some how with severe cognitive disability pertaining to logic, intellect and emotions, communication skills and coordination.

39. I did face difficulties and obstacles in accessing treatment for Hepatitis C. I had to fight for them to give me Interferon. I remember feeling angry at the time because I needed them to treat me and my condition was getting worse. I believe I should have been treated earlier. It took around 14 months to get funding to treat me the second time around.

40. My medical notes show that before I started Pegylated Interferon in February 2001, Dr Hay applied to the NHS and Schering Plough for funding for my treatment and there was an argument as to whether the NHS would fund my treatment because it was costly. I refer to exhibit WITN0428006.

41. I do not know if I should have been given any other forms of treatment for Hepatitis C. I was never told much about the infection. I didn't know anything.

42. There were many mental and physical effects due to the treatments that I received for Hepatitis C. The treatments made me very unwell. The side effects were similar during both treatments, but worse the second time.

43. While undergoing treatment, I felt very ill. I suffered from nausea and felt sick constantly. I lost my appetite and a lot of weight. I started my second treatment weighing 96KG and my weight fell to 80KG because of the treatment. I felt very tired all the time. I became very withdrawn and I didn't want to know anybody. After taking the injections all I did was go to bed and stay there. I suffered from depression for which I was prescribed anti depressants. I did not sleep well and I was prescribed sleeping tablets. I had

other issues such as impotence, shortness of breath and hair loss. I became totally confused with the severe depression I suffered and became irritable and angry.

44. I was working before I started my first treatment for Hepatitis C but I was forced to stop as a result of the treatment and the side effects. I was working at a factory at the time.

45. Since my diagnosis, I have isolated myself and whilst I am in contact with my mother on occasions, I am no longer in contact with other members of my family.

46. Having Hepatitis C has affected my ability to work. I have many medical conditions and I believe the Hepatitis C is the cause of most of my issues. Not being able to work has meant that I have struggled financially.

Section 6. Treatment/care/support

47. My Hepatitis C infection has not caused me any difficulties with accessing other medical treatment. Getting dental work done involves the same rigmarole each time of the dental hospital writing first to the MRI to request FVIII before they touch my teeth. This is due to my haemophilia though, not to Hepatitis C.

48. I have never been offered any counselling or psychological support. It has never been made available to me in consequence of what happened. I was never told that it was an option. I should have been offered counselling, I believe it would have helped me. I am pushing for a referral to the Neuropsychology Assessment Team and I am presently waiting for an appointment.

49. I have had no help from anyone, I have had to do it all on my own. I have only received help in the last 3 years when my friend GRO-B started helping me out with paperwork and doing things for me.

Section 7. Financial Assistance

50. Dr Hay told me I would get a one off payment of £20,000 through the Skipton Fund. Dr Hay told me I was getting the money and just had to wait. I didn't have to fill out an application myself. The process was straight forward.

51. I received a payment from the Skipton Fund of £20,000 in 2011.

52. The next payment I received was from the Caxton Foundation in 2015. I received the sum of £166.67. I didn't make any application.

53. In 2017, I received £3,500 from the Skipton Fund. I also received 3 additional payments from the Skipton Fund in April, May and June 2017 of £250, £250 and £257.50 respectively.

54. Since October or November of 2018 I started to receive funding from the England Infected Blood Support Scheme (EIBSS). The funding comes in the form of monthly payments of £333.30 per month. I didn't have to apply for this either In July this year the payments increased to £1538.17 per month.

55. I made an application to the EIBSS for the Stage 2 payment as I have cirrhosis of the liver. I did not know about the Stage 2 payment; I was not made aware of this until recently. However, my application has been refused. I attach at Exhibit WITN0428008 a copy of the letter from the EIBSS dated 24 October 2019 turning my application down. I attach at Exhibit WITN0428009 a copy letter from my hepatologist at the MRI dated 26th June 2019.

56. The money I have received has not been sufficient and I have struggled financially.

Section 8. Other Issues

57. I believe I should have been given more information about the infections I have received.

58. I should have been told earlier about my infections. I feel that the hospitals only tell me what they want to tell me. Even though it's my body.

59. From 1965 to 1997 a huge chunk of my Haematology records are missing which I believe to be very suspicious. It raises a question about what is being hidden.

60. The truth needs to come out. We did not ask for the diseases we were given. I believe haemophiliacs were used as guinea pigs.

61. Everyone who has been infected has been categorised - Stage 1, Stage 2 etc. Everyone in this world is different. We have all been given tainted blood but outcomes are different.

62. Many people have passed away already as a result of infected blood and can no longer defend themselves or tell their story. This Inquiry should not go on for years, people are dying now and this needs to be sorted immediately. The payments need to be sorted out now. It's no good helping us when it's too late.

63. I believe I should have received more compensation to help me.

64. I would like to thank Sir Brian Longstaff for chairing the Inquiry and Dianne Johnson for chairing the Haemophilia Society.

65. I would also like to thank my friend GRO-B who has helped me through all of this.

Anonymity

66. I wish to remain anonymous.

67. I am unable to give oral evidence to the Inquiry as I feel I would not understand the questions put to me. Whilst I would like to have given evidence I do not feel I am able to due to my cognitive disability..

Statement of Truth

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

Signed. GRO-B ....

GRO-B

Dated.... 5-12-19 ....