ANONYMOUS

Witness Name: GRO-B
Statement No: WITN1446001
Exhibits: WITN1446002 - WITN1446016
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 My address is GRO-B GRO-B. My date of birth is GRO-B I am married to GRO-B and we have one child, who is GRO-B years old. I am employed full-time as a GRO-B

2. I was infected with Hepatitis B and Hepatitis C as a result of receiving contaminated blood products. I was treated with plasma-derived Factor IX Concentrate (Factor IX). I have also received blood transfusions. I have cleared both Hepatitis B and C naturally.

3. This witness statement has been prepared without the benefit of access to my full medical records. In so far as I have been provided with incomplete medical records I have referred to relevant documents in this statement.

4. I have been advised that my medical records from the GRO-B GRO-B have been destroyed,

although some copy letters appear in my GRO-B GRO-B records.

5. Information held in the National Haemophilia Database is partial and incomplete. Treatment data is missing between 1974 and 1980 and between 1989 and 1996. There are no records of batch numbers.

6. The results of my HIV tests are incomplete and inconsistent with medical records (see para 25). The Hepatitis C lookback data is partial and incomplete and there is no record of Hepatitis tests. I have exhibited to this statement extracts from the UK National Haemophilia Database at Exhibit WITN1446002.

Section 2. How affected

7. I was born in GRO-B and this is also where I spent my early years. I was diagnosed with moderate Haemophilia B (also known as "Christmas Disease") at the age of 15 months. I fell down some stairs and sustained a cut to my lip which would not heal and for which I was treated at the GRO-B GRO-B at the GRO-B GRO-B GRO-B.

8. I have exhibited to this statement marked WITN1446003 a copy of letter from GRO-B dated GRO-B and a copy of a letter from GRO-B dated GRO-B GRO-B. These letters confirm that I was diagnosed with Christmas Disease. The letters also confirm that I was given blood transfusions and fresh plasma on 'various' occasions following admission to GRO-B on 15 January 1976 and that I was treated with Factor IX at GRO-B

9. In my earlier years I was cared for jointly by the Paediatric Clinic at GRO-B and the Haematology Department at the GRO-B GRO-B. I was under the care of GRO-B

10. From the age of GRO-B I was treated in GRO-B under the care of GRO-B While under the care of GRO-B I also received treatment at the Haemophilia Centre in GRO-B GRO-B During my time at university from GRO-B until GRO-B I received some of my care and treatment at GRO-B

11. I was first treated with Factor IX when I was GRO-B old. After this, I was treated with plasma-derived Factor IX whenever I had a bleed or an injury. From around GRO-B I was taught how to self-administer the treatment, so that I was able to attend to my injuries myself at home. I was given bottles of plasma derived Factor IX, needles and swabs to self-administer the treatment.

12. I have exhibited to this statement marked WITN1446004 copies of handwritten hospital notes dated between GRO-B. These notes include examples of the batch numbers of the Factor IX treatments that were given to me during that period, both at the hospital and at home. These records are likely to be incomplete. Also included in exhibit WITN1446004 is a handwritten list of batch numbers that were provided as records of home treatment in 1990 and 1991, which are included in my records.

13. My parents were aware that there was a risk of infection to me from being treated with Factor IX. I am unsure when they first became aware of the risk. It appears from my medical records that my parents became aware of the risk that I could be infected with the Human Immunodeficiency Virus (HIV) around GRO-B or so, and that they were aware of a risk of hepatitis prior to this, possibly from the 1970s. I have exhibited to this statement marked WITN1446005 a copy of a bulletin from the Haemophilia Society dated GRO-B which states that there is a significantly increased risk of hepatitis from the use of commercial Factor VIII concentrate from America compared to British products. The bulletin refers to a Granada TV programme "World in Action" in GRO-B which featured an investigation into the business of paid blood donors and the commercial production of Factor VIII in America. I understand that the issues surrounding Factor IX were the same.

14. My parents were told that I had been infected with Hepatitis B virus in GRO-B when I was GRO-B old. I have exhibited to this statement marked WITN1446006 copies of two letters from the GRO-B one of which is addressed to my father. The letters confirm that I was infected with Hepatitis B sometime between GRO-B The letter to my father says, "Until recently, our main concern was with hepatitis." and alludes to a new risk in relation to which my immune function was to be tested. The letter further states that I was at risk of getting other forms of hepatitis.

15. I remember that my parents were very fearful of me contracting HIV. This was around the time when the Government started advertising that HIV and Acquired Immune Deficiency Syndrome (AIDS) was quite prominent in the media. HIV and AIDS also quickly became associated with Haemophilia and blood products.

16. There were many letters exchanged between my father and the doctors in GRO-B about this. My father did a lot of research into the condition and he pursued information about the risks associated with being treated with blood products. He also actively lobbied the doctors and the Haemophilia Society for more information and for safer treatments. The doctors seemed to be quite open and honest with my parents about the risks, and that they could not give them any guarantees about the safety of blood products.

17. I recall talking to one of the doctors in my teens. The doctor was very open about the risks and said that I needed the treatment whenever I had a bleed or I would end up disabled. He also mentioned to me the risk of infection. GRO-B GRO-B were very clear that if I did not take enough Factor IX, then there was a risk of damage to my joints.

18. Having read through some of the letters in my medical records, it is clear to me that some of the doctors understood the risks associated with blood products but were torn between treating my haemophilia and not being able to prevent these risks. This must have been awful for those doctors to deal with.

19. My father asked my doctor to reduce the dosage of Factor IX given to me because he believed that this would reduce the chances of me contracting HIV. I have attached to this statement marked WITN1446008 a copy of a document from GRO-B dated GRO-B which records my father's concerns about the risk of infection from clotting factor concentrates.

20. Because of the risk of infection and also because I also generally did not like to give myself injections, I did not do it unless I absolutely had to, which resulted in multiple bleeds in my right ankle and elbow. This later led me to developing arthritis in both joints.

21. We were made aware of the existence of heat-treated blood products, and the fact that it significantly reduces the risk of infection, but that it did not eliminate it. To my understanding, this was not something that was made readily available to all haemophiliacs by the UK government due to funding issues. I did eventually get heat-treated Factor IX, but I am not sure when exactly.

22. I have attached to this statement marked WITN1446007 the following documents in support:

    a) A copy of a letter from GRO-B to the Minister for Health and Security dated GRO-B in which he requests funds for heat treated products in order to eliminate the risk of infection to patients with congenital blood diseases such as haemophilia;
    b) A copy of a letter from the GRO-B GRO-B regarding precautions being taken to reduce the risk of AIDS from blood donations.
    c) A copy of a letter from GRO-B illustrating that heat treated Factor IX was only available for patients undergoing surgery and was not universally available in 1992.

23. From around GRO-B I was treated with recombinant Factor IX. I refer to letters dated GRO-B which confirm this and which I have attached to this statement marked WITN1446010.

24. I was fortunate. It was not until 2003 that recombinant Factor IX became available to all adults in the UK. I have exhibited at WITN1446009, a copy of an article from the Magazine of the Haemophilia Society dated 2003, which discussed this matter in more detail.

25. I grew up knowing that I had had Hepatitis B and that I was at risk of HIV and AIDS. I spent many years living in fear of contracting HIV and AIDS.

26. I have attached to this statement marked WITN1446011 copies of letters from GRO-B which confirm that my blood tests showed that I was negative for HTLV III (the AIDS virus). The letters indicate that, as of December 1985, heat treated materials were available.

27. I have attached to this statement marked WITN1446012 a copy of a blood test result from GRO-B which shows that I tested positive for Hepatitis C anti-bodies on GRO-B. I have also attached to this statement marked WITN1446013 two letters from GRO-B GRO-B which refer to my Hepatitis C infection.

28. To be best of my recollection, it was not until GRO-B that I was told that I had contracted Hepatitis C. I was GRO-B years old at the time and under the care of GRO-B I attended a routine appointment at the GRO-B where I saw GRO-B and he told me about my Hepatitis C infection. I didn't understand what Hepatitis C was specifically and I assumed it to be similar to Hepatitis B. I had grown up knowing that I had Hepatitis B, so I had a general idea of what Hepatitis was. Finding out that I had Hepatitis C was not a big surprise to me. I was not surprised that I had contracted another Hepatitis infection. I had lived in fear of contracting HIV and developing AIDS for so long that my only thought at the time was that Hepatitis C was the lesser of two evils and I felt lucky that I had not contracted HIV.

29. I was told that the virus could lead to liver damage and I needed to undergo further tests before receiving treatment for it. I have attached to this statement marked WITN1446014 a letter from GRO-B

GRO-B which refers to my Hepatitis C infection and possibility of treatment for this.

30. Fortunately, prior to starting my treatment I was told that my body had cleared Hepatitis C naturally. I do not know how long the virus was active in my body for or when it was cleared.

31. The letters from GRO-B (referenced above) state that I had Hepatitis C antibodies in 1995. As of my last blood test in September 2018, the virus was found to be inactive. I have attached to this statement marked WITN1446015 a copy of a letter from GRO-B GRO-B which encloses details of that blood test.

32. I only told my parents about my Hepatitis C infection in 2018 which came as a huge shock to them.

Section 3. Other Infections

33. My notes show that I had glandular fever in GRO-B but I do not recall being told of this.

34. As far as I am aware, I have not contracted any other infections.

35. I was made aware by GRO-B that I am at risk of vCJD, although I understand that I did not receive an implicated batch. I have exhibited to this statement marked WITN1446016, two letters from GRO-B dated GRO-B GRO-B.

Section 4. Consent

36. I believe I was made aware of the risks of infection by my doctors – certainly in regards to HIV – and I do not believe I was treated with Factor IX without being given adequate or full information.

37. I don't know if my parents gave consent to the doctors for me to be tested for Hepatitis B, as well as for my blood to be routinely tested.

38. I do not recall the circumstances surrounding my being tested for Hepatitis C in GRO-B and cannot say whether or not I consented to being tested for this infection at that time.

39. I do not recall giving consent to be tested for glandular fever and neither do my parents.

40. I have given consent to have my blood tested for Hepatitis C on subsequent occasions.

Section 5. Impact

41. My parents were not aware that I had Hepatitis B until after I had cleared it. I refer to WITN1446006.

42. My family and I were aware that I had contracted Hepatitis B and that I was at risk of contracting HIV and AIDS.

43. During my teenage years I was fearful of contracting HIV and AIDS. I constantly expected to be told that I had this infection and I tried to prepare myself psychologically for how I would deal with it. I worried constantly about getting HIV and AIDS. I even planned a campaign for AIDS awareness that I would pursue in case I was to contract it. I never told my parents about this. The risk of me becoming infected with HIV was always in the background in my family but it was not something that we spoke much about.

44. I found it very stressful growing up with the possibility of contracting HIV and AIDS and what that could mean for me and my family. I feel very lucky not to have caught HIV. However, psychologically, the fear of becoming infected with HIV was very debilitating. I believe this fear hindered me tremendously. Even now, I still think about what my life would have been like if I had become infected with HIV.

45. I did not find out about my Hepatitis C infection until I was GRO-B old. I probably had the infection for many years before this. Finding out that I had this infection has helped explain some of the problems I have had in the past.

46. I recall a period of ill health in or around GRO-B which started not long after my shoulder operation in GRO-B. I remember that after the operation I felt very tired and withdrawn.

47. I have had a number of episodes of bad flu like illnesses which I wonder, with hindsight, may have been down to my Hepatitis C infection. In GRO-B the year I turned GRO-B I remember being very ill around Easter time. I lost my voice and had bad flu symptoms. According to my medical records, I had routine tests during this period which indicated that I might have glandular fever, although I wasn't told this at that time. I wonder now if perhaps my symptoms were due to having contracted Hepatitis C.

48. That same year I started to suffer from anxiety, low mood, inability to sleep, feeling withdrawn, lack of appetite, and problems with concentration. I believe these problems could have been caused by my Hepatitis C infection.

49. When I was GRO-B years old I was diagnosed with depression by my GP. I believe that there might be a correlation between my depression and my Hepatitis infections. I was on antidepressants for around eight years.

50. I stopped taking antidepressants when I was around GRO-B years old. I found that they were not helping me and I slowly weaned myself off them, without any medical support. I still experience anxiety, but I try to just get on with my life. I believe there was a link between my Hepatitis C infection and my depression and this is why the antidepressants did not help me. If my Hepatitis C infection had been identified and treated earlier I believe my depression could have been dealt with more effectively.

51. As a result of my depression I lacked confidence to make friends and to ask girls out. I did not have a girlfriend for the entire period I was on anti-depressants. This is partly because I did not think it was fair to have a girlfriend and put that burden

on someone else. Then, when I found out about my Hepatitis C infection, I was also unsure about the risk of passing it on, even when I had been told I had cleared it. I did eventually go on to meet my wife when I was about GRO-B years old.

52. I understand that my parents asked doctors to treat me with an adequate amount of Factor IX to deal with bleeds, but not to administer too much in order to reduce the chances of me contracting HIV and AIDS. It must have been awful for them to know that treatment meant to stop bleeds could also have given me an infection. This put them between a rock and a hard place.

53. Doctors did advise that not taking enough Factor IX could result in damage to my joints. During my teens I had regular bleeds into my right ankle and left elbow which I did not treat as frequently as I should have had. This has unfortunately caused me to suffer from arthritis in both joints. I believe that had the risk of HIV and AIDS not been present, I would have treated my ankle and elbows bleeds more frequently and may not have had the joint problems I live with now.

54. My father was always afraid of me being infected with HIV. He did a lot of research into the risk of me being infected with HIV and AIDS in the GRO-B and he lived in fear of my treatments infecting me with HIV. He spent a lot of time writing to doctors and to the Haemophilia Society and he lobbied to get me first, on to heat treated Factor IX and then on to recombinant Factor IX.

55. My mother was an Associate Member of the Institute of Biology during the early 1980's and recalls being told about HIV and AIDS at a conference at Bangor University. She was asked by the Institute to lobby her local pathology lab by putting up HIV/AIDS posters to raise awareness.

56. I feel that my relationship with my father suffered as a result of his reasonable fear that I could be infected with HIV. He was trying to protect me but his fear was passed on to me and I lived in fear too. The fact that he asked my doctor to restrict the dose of Factor IX I was given caused some tension between us. I believe if the risk and fear of infection had not been present at that time, I may have been treated more effectively at the time that I had bleeds and I may not have the joint problems I have now.

57. My parents paid for a period of inpatient psychiatric treatment and counselling for me. This affected them financially at that time.

58. I was an adult when I found out about my Hepatitis C infection and therefore my parents were not informed about it by the doctors. I did not tell my parents about my infection and I kept it to myself. It was only after the Infected Blood Inquiry started that I told them about my infection in 2018.

59. Growing up, my father discouraged me from telling anyone about my haemophilia, probably because of the stigma attached to HIV and AIDS at that time and the fact that people were beginning to link haemophilia with HIV and AIDS. In the 1970s and 1980s there was a provocative advertising campaign about AIDS and this created a culture of fear which affected the haemophilia population. My father was afraid that if I told people I had haemophilia they might think I also had AIDS. No one knew that I had haemophilia, only my extended family.

60. Not being able to talk to anyone about the difficulties I had affected me psychologically. I could not share my experiences with anyone and so I had very little support. I had a younger brother who does not have haemophilia and I could not talk to him about my illness. It was not a taboo topic in our household as such, but we did not tend to talk about it at all, unless I needed an injection. The only person that I could talk to was my mother.

61. In primary school, the other kids knew that I bruised easily, but that was the extent of it. In secondary school my teachers were told I had haemophilia, but, as far as I am aware, my fellow students didn't know. My doctors advised my parents that engaging in sporting activity was risky and consequently I was not allowed to participate in football at secondary school. Not being able to feel like I could tell anyone why I wasn't able to play football caused my psychological distress.

62. I did not know anyone else with haemophilia and I felt isolated. The first time I met anyone with haemophilia was when I went on a sports trip to Italy which was organised by the Northern Regional Haemophilia Service. This trip, which was

led by physiotherapists, gave me much greater confidence in my physical ability to participate in sports. Unfortunately I did not keep in contact with any of the children I met on that trip.

63. As a result of the challenges I was facing with depression, I only got one A-Level the first time round and went on to re-sit my A-Levels twice achieving a C, D and E in the end. This was in stark contrast with my GCSE results, where I achieved three A's and five B's,

64. In order to go to university I had to go through the clearing system, which affected my confidence further. I found the set back of failing my A-levels twice and having to go through clearing embarrassing.

65. During my first year at university I had a bad bleed in my left elbow and my flat mates came to visit me in hospital. I decided to tell them that I had haemophilia. Being able to speak to my friends about my haemophilia was a big relief.

66. Because I started university late I got on to the career ladder two years later than everyone else. When I left university, it was very hard for me to find a graduate job and I took a number of low paid jobs, because I didn't have the confidence to move away from home and look for better opportunities.

67. I found it hard to move away from home to go and work, because I always felt safe there. This made me relapse heavily in to my depression in my early twenties.

68. It was only when I was in my late twenties and early thirties that I was able to take control of my life. I decided to undertake an GRO-B which I completed between GRO-B Completing an GRO-B helped me to pursue a career change and do what I wanted to do with my life.

69. For my entire life I have been plagued with the feeling of what might have been, in terms of my studies, my work and my relationships. The effect of this on me was psychologically damaging. I knew I could be doing better.

Section 6. Treatment/Care/Support

70. I spontaneously cleared both Hepatitis B and C infections without treatment.

71. At the time I was diagnosed with depression, there was no consideration about the impact of my haemophilia, or the risk of infection, on my mental health. And no psychological support was offered to me when I was notified of my infection with Hepatitis C. I understand that the Welsh Infected Blood Support Scheme (WIBSS) is currently in the process of setting up a psychology service.

72. Hepatitis C was not explored as having an impact on my mental health during my treatment for depression, so I struggled to make sense of it, attributing it to other factors. If the correlation between Hepatitis C and depression had been explored I think that would have helped me.

Section 7. Financial Assistance

73. In 2006 I received £20,000 as a one-off payment from the Skipton Fund. One of my doctors applied on my behalf to the Skipton Fund after I was told I was infected with Hepatitis C. I didn't actively seek financial support but was encouraged by the doctors to apply to the Fund and receive the financial support available.

74. I currently receive around GRO-B as a monthly payment.

75. I did not find any obstacles in applying for financial assistance.

76. I recently received a letter from the WIBSS, which has taken over payments for Welsh patients previously supported by the Skipton Fund. It offered enhanced payments if I self-assess that I am suffering from post-traumatic stress or significant mental health issues due to my infection. I question why this is not universal for all patients who have experienced mental health problems.

77. Whilst enhanced payments for post-traumatic stress or significant mental health issues are obviously welcome, there is still no recognition of the impact that this scandal has had on patients' mental health in the past.

Section 8. Other Issues

78. The Inquiry should look into the availability and provision of Government funding for heat treated and recombinant Factor IX across the UK during the 1980s and 1990s. The evidence I provide with this statement clearly demonstrates that funding was an issue.

79. The Inquiry also needs to look into the role of pharmaceutical companies which provided blood products to the NHS and the reasons why the UK were not self sufficient in the supply of blood products. Why did the need to purchase Factor IX products from the US arise?

80. I strongly believe that Haemophilia services should be physiotherapy-led rather than Haematology led as physiotherapists are best trained to deal with the joint and muscle problems resulting from bleeds.

Anonymity, Disclosure and Redaction

81. I confirm that I wish to apply for anonymity and that I understand a redacted version of this statement will be published and disclosed as part of the Inquiry.

82. I do not wish to be called to give oral evidence at this stage.

Statement of Truth

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

Signed. GRO-B ....

Dated. 29/09/19