Witness Name: GRO-B
Statement No: WITN1282001
Exhibits: 0
Dated: December 2018

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 date of birth is GRO-B 1970 and I live at GRO-B GRO-B with my wife GRO-B I have GRO-B children in total.

2. 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 set out in the medical chronology at the end of this statement.

Section 2. How infected

3. I was diagnosed with mild/moderate Haemophilia A when I was 11 years old. I am the only one in my family to be diagnosed with haemophilia and it was traced back to my GRO-B

4. I was treated with Factor VIII (FVIII) at various different hospitals when I was a child as I moved around because my father was in the army. I was initially treated at GRO-B and then I was treated at GRO-B GRO-B. From GRO-B GRO-B I was treated at GRO-B (WH). I recall I was also treated on 1 occasion at GRO-B GRO-B.

5. I was given FVIII at the above hospitals for either tooth extractions or when I had knocks and bleeds.

6. I believe I was given contaminated FVIII blood products between the ages of 11 and 15 either at GRO-B or GRO-B.

7. No advice was given to me or my GRO-B at the time about the use of or risks associated with blood products.

8. I was infected with Human Immunodeficiency Virus (HIV) and Hepatitis C (Hep C) as a result of being given contaminated blood products.

9. I recall attending the GRO-B in GRO-B for a tooth extraction and that the date of the appointment had been changed numerous times. I was at the hospital for about a week and a half whilst they tried to extract the tooth. In the end, I did not have the tooth extraction and I was sent home without an explanation.

10. In GRO-B, my GRO-B received a letter from GRO-B stating that we had to attend the hospital. The letter did not state why we had to attend. We attended the appointment and I was told to leave the room. The doctor spoke to my mother alone and told her that I was HIV positive. This was the first time that my mother was told that I was HIV positive. I was called back into the room and I saw my mother was crying. She was so upset with the news that she asked the doctor to tell me that I was HIV positive. I went numb when he told me. I was 15 at the time and I was still at school. I was told that there was no cure or treatment and I was just left to deal with it on my own, which made me

very angry. No other information was given to me about the infection or how to manage the infection.

11. GRO-B. Initially, I did not tell her about my HIV status. She found out when my GRO-B. The GRO-B then advised us to attend the hospital. It was at this appointment that the doctor told me that HIV could be sexually transmitted. My wife was given cream to use prior to sexual intercourse and I was given protection to use.

12. In or about 1996 I attended an appointment at GRO-B to have a GRO-B removed and I was given my medical records by a nurse at the Haemophilia Centre to take to the appointment. Whilst I was sitting waiting for my appointment I read through my notes. I found a test result stating I had tested positive for Hepatitis C (Hep C). No one told me that I was being tested for Hep C. I was shocked and devastated seeing a positive result for Hep C in my medical records. I confronted the doctor at the Haemophilia Centre the same day and he told me that I was told when I first tested positive for Hep C. This was not true, nobody had told me. The doctor told me I had nothing to worry about because I had it for a while. I was just told that it can affect the liver and it could be sexually transmitted. I was not provided with any other information to understand the infection or manage the infection. I only realised how serious the infection was at a later stage when I was given more information.

13. I believe that the doctors were aware of the risks involved with infected blood products but they failed to warn me. I believe I should have been told in the early 1980s.

14. I believe that I should have been told about the Hep C when I first tested positive. At GRO-B the haemophilia doctors would change and I saw two different doctors within a year. The doctors said the reason I was not told was because there was a change over of doctors.

Section 3. Other Infections

15. In 2004 I received a letter from GRO-B stating that I had been given a batch of FVIII which contained blood from someone who had died from vCJD. I then phoned the hospital but they merely repeated what was in the letter. They were very dismissive.

16. I was upset when I received the letter as there had been a lot of press about vCJD and 'mad cow disease'. I felt a lot of anger again. I have not received any further information.

Section 4. Consent

17. I believe that I have been treated and tested without my knowledge, consent and without being given adequate information. I was not told I was being tested for HIV and Hep C, I was just told when I tested positive.

18. I also believe that I have been treated and tested for the purposes of research.

Section 5. Impact of the Infection

19. Trying to deal with HIV at the age of 15 was very hard. I had anger issues prior to my diagnoses and being told that I tested positive for HIV and Hep C caused further anger issues. I was always thinking about the infections and it completely changed my outlook on life. The doctors attitude towards HIV was horrendous. They made me feel as though it was my fault that I contracted the infections. I was given a treatment that was suppose to help me, but instead it infected me with deadly infections.

20. I started drinking a lot of alcohol to block it out. When the doctors told me that I would only live until the age of 21, it changed me. I lived for the moment because I thought I was going to die. I feel lucky to have a wife and family that supported me and kept me going.

21. Before I was diagnosed with HIV I was always sick and the doctors believed I had asthma. I suffered from flu like symptoms, memory loss and fatigue. My body ached all the time. I lost a lot of weight and at my lightest I was 7 ½ stones. My haemoglobin levels dropped and I was given medication for it. I had muscle wastage around my knees and elbows. The doctors now believe that the above symptoms were all HIV related.

22. In 1992 I had pneumonia. I was told that my viral load was in the millions. The doctors thought I was going to die. Luckily a new treatment, Azidothymidine (AZT) had just been discovered and it was given to me straightaway. However, after 3 years the AZT stopped working so I was given a different drug called Didanosine (DDI). This treatment was awful; the tablet was large and it had to be dissolved in water before it was consumed. I have had many different HIV treatments since 1992 and I have had side effects from each treatment, these include: being sick, feeling dizzy, weird rashes and weight loss.

23. Furthermore, I have a shadow on one of my lungs. The doctors are not sure what it is. I believe this is related to HIV.

24. Between 2002 and 2006, I was told that Interferon treatment was available for Hep C. I was on the treatment for approximately 10 months and it was hell. The treatment consisted of weekly injections and tablets. When I had the injection I felt awful for about 4/5 days and found it difficult to get out of bed. I would start to feel better near to the end of the week, but then the next injection was due and I suffered the same symptoms again. I have had a fear of needles from a young age, so when I had to inject myself repeatedly it made me extremely anxious. The treatment was unbearable. I believe there was no alternative treatment available at the time.

25. The treatment affected me mentally and physically. My body constantly ached and I was sick. I was given anti-sickness medication to help with my

symptoms, but the tablets made me drowsy. I had anaemia and flu like symptoms. I did not want to do anything and I completely lost my appetite. My wife said the treatment completely changed me GRO-B GRO-B.

26. I had to go back and forth to the hospital to have regular blood tests. I told the doctors about the side-effects of the treatment and they just said it was to be expected. I told them a few times that I wanted to come off the treatment but they told me to continue with it, which I did.

27. I was told that the treatment had cleared the Hep C. Approximately 3 months later I had a blood test and I was told that the Hep C had come back. I asked if there was anymore treatment but they said this was my one bite of the apple.

28. I have seen a hepatologist and she told me that I have been approved for a new treatment that is available. However, I am very reluctant to start the new course of treatment because of the first treatment and I want to do my own research before I accept any future treatment.

29. At my routine appointments, I noticed a bright red sticker on my medical notes. I believe this was a warning for the doctors to show that I had HIV. I understand why they needed the warning, but it made me feel very isolated.

30. I believe my infections also impacted on my medical and dental care. I recall some of the nurses at the hospital refused to treat me because of my status. My dental appointments were cancelled at the last minute. It was very frustrating.

31. I believe my infected status had also affected my family's medical care. When my wife gave birth to our first son some of her afterbirth fluids went onto the nurse. We were told that the nurse was not allowed to work for 6 months whilst she was being tested. They would not let our baby into the neonatal

unit of the hospital and she had to stay in a private room. The staff were aware that my wife did not have HIV, but she was still treated differently.

32. Eventually, my wife and I had to tell the children about my infected status because we did not want them to find out from someone else. It was not nice telling them. Everything that we did as a family had to revolve around me.

33. There was a lot of stigma associated with HIV and Hep C. I found it very difficult to talk to people when I was first diagnosed and did not tell anyone that I had HIV because I was scared of the reaction. I was very active and very outgoing and after the diagnoses I stayed indoors most of the time. I believed that if I mentioned that I was HIV positive people would instantly think I was a drug user.

34. In or about 1986 I attended a routine appointment at GRO-B and I recall the doctor wearing what looked liked a space suit, covered head to toe. I asked him why he was wearing that outfit and he said it was for his own protection. I felt very angry and degraded.

35. I still believe stigma is associated with the infections. GRO-B

GRO-B

36. GRO-B

37. The infection has had a big impact on my education. I was doing really well at school but then I dropped out after I was diagnosed with HIV. I did not see the point of having an education as the doctors told me that I would be dead before I was 21.

38. Being diagnosed as a haemophiliac at the age of 11 was difficult. I could not play any contact sports, so when I was diagnosed with HIV I just felt more isolated because I was not allowed to take part in any sporting activities at all.

39. I have not worked since GRO-B because of my illness. I have applied for jobs, but I believe I was not given the opportunity because of my HIV status. Not been able to work has affected me financially.

40. I cannot get a mortgage because I cannot get life insurance. I got a quote for £500 a month, but I could not afford it. I was able to find a company (Insurancewith) that would give me travel insurance at a reasonable price. Before I found this company the travel insurance would cost over £200 just to go to Spain for a week.

Section 6. Treatment/care/support

41. The hospitals have been very good to me. I was always told when new treatment was available. The also arranged for a nurse to come out to see me when I was unable to travel.

42. I have had counselling a few times, however, the counsellors said there was nothing they could do to help. I first had counselling at school from the school counsellor. I was not offered any counseling from the hospital when I was diagnosed with HIV.

43. When I was diagnosed with Hep C the hospital offered anger management treatment. The treatment did not really help.

Section 7. Financial Assistance

44. I found out about the Macfarlane Trust through the Haemophilia Society in 1988.

45. When the Macfarlane Trust first started they helped me financially with a GRO-B I also received financial help towards a GRO-B However, they required quotes and I found it difficult telling the companies why I needed the quotes.

46. I also received a lump sum payment of £60,000 from the Trust in or about the 1990s and I recall signing a wavier. I was involved in a litigation claim at the time and the solicitor said I had no choice but to sign it in order to get the payment. They were very pushy in relation to signing the waiver.

47. I receive a monthly payment of £1,682 from the, which started in the early 1990s. The payment increased gradually and after the Archer Inquiry.

48. The Trust told me about the Skipton Fund and I received Stage 1 payment in the sum of £20,000 in or about 2004.

49. At the start of this year I have received £1,500 a month from the Skipton Fund. I did not have any difficulties applying for this because the Trust was already aware that I was co-infected. My wife filled in a lot of the forms for me.

50. I now receive the above monthly payments from EIBSS.

51. I believe the money that I receive is not enough for what we have been through. It is not enough to live a comfortable life.

52. In or about 1991 I have also received a sum of £15,000 from a litigation case.

Section 8. Other Issues

53. During the litigation I was told that the doctors could have treated me with DDAVP but I was given FVIII. I believe they wanted to use me as an experiment.

Anonymity, disclosure and redaction

54. I confirm that I do wish to apply for anonymity.

Statement of Truth

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

Signed GRO-B ....

Dated ..18.12.18...