Witness Name: GRO-B
Statement No.: WITN0865001
Exhibits: N/A
Dated: 16 April 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 25 March 2019.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B I am 56 years of age having been born GRO-B 1962. My address is known to the Inquiry. I have been married to my wife GRO-B for 31 years and we have a son GRO-B together. I am a former civil servant having recently retired.

2. I have severe haemophilia A and I was infected with HIV and hepatitis C ("HCV") as a result of receiving infected blood products for treatment of my haemophilia.

3. I intend to speak about the nature of my infections and how the infections have impacted me, my family and our lives together.

Section 2. How Infected

4. I was diagnosed with severe haemophilia A in 1965 when I was three years old. At the time, I was under the care of the Hammersmith Hospital. Initially, the Hammersmith Hospital could not diagnose my haemophilia and referred me to the Oxford

Haemophilia Centre where I saw Dr Charles Rizza. Dr Rizza diagnosed my haemophilia immediately.

5. After my diagnosis I was referred to the Royal Free Hospital. Initially, I was under the care of the Katherine Dormandy and later under Dr Eleanor Goldman and Dr Christine Lee's care. Initially, my haemophilia was treated at the hospital with cryoprecipitate, which I used on demand whenever I had a bleed. I had regular bleeds, often once a week which required multiple trips to the hospital.

6. I am not certain when my treatment switched from cryoprecipitate to concentrated Factor VIII blood products. Whenever a new treatment came along my parents and I would agree to use it as soon as it was offered. It is likely that I started being treated with Factor VIII when it first became available. To this day, I am happy to volunteer to trial new medicines.

7. I have used blood and blood products on more occasions than I can count. Currently, my haemophilia is treated prophylactically with a synthetic Factor VIII product. Treatment options have come a very long way since I was first diagnosed with haemophilia.

8. As far as I am aware, my parents were never provided with any information about the risk of being exposed to infection from blood products. My treating doctors regularly tested and reviewed my bloods but we were not told what exactly my blood was being tested for other than for general monitoring purposes.

9. In the mid 1970s I attended the Royal Free Hospital for a routine review with Dr Lee. During the review Dr Lee told me I had tested positive for hepatitis B ("HBV") infection. I don't recall being given much information about the disease other than my doctors would continue to monitor the infection.

10. In late 1976, during another routine review with Dr Lee, I was advised I had tested positive for hepatitis C ("HCV") (or as it was known then, non-A non-B hepatitis). I had not been told my blood was being tested for HCV and the diagnosis came as a shock. Dr Lee told me that there was no HCV treatment available but that she would continue to monitor my blood levels and keep an eye on it.

11. Dr Lee told me I had received the infections as a result of receiving infected blood products. I was never told which batch or product infected me.

12. I was shocked by my diagnoses but responded pragmatically. I had the attitude that I just needed to get on with it and not let it weigh me down. I was conscious of the fact that the blood products I had received were necessary and potentially life saving.

13. In 1985 Dr Lee advised me that I had tested positive for HIV. She advised me that a look back exercise had identified I was infected in early 1980 by contaminated Factor VIII products. As with my HCV infection, Dr Lee told me that there was no treatment available for the HIV. She told me the hospital would continue to monitor my health.

14. Prior to my diagnoses, I was never told that HCV, HBV or HIV might be present in the blood products.

15. At the time of my HIV diagnosis, HIV was frequently in the media but not widely understood. I knew it was a potentially deadly, infectious disease but I didn't know much else about it other than what had been reported in the media. I was shocked and upset that I had been infected but I was determined not to let the diagnosis consume me and again took the attitude that I needed to get on with it.

16. Dr Lee and Dr Goldman gave me very limited information about my HCV, HBV and HIV infections. I don't think the medical profession really understood the infections themselves at the time.

17. I received very little information about how to manage the infections other than to come back to hospital for a review every three months. At the time my doctors never told me how the infections were potentially transmitted or the possible risks of infecting other people. At the time of my HCV diagnosis, my mother was still administering my Factor VIII products. At no point was she warned to wear gloves when administering the treatment or avoid coming into contact with my blood. During the mid-1970s, my mother joined the phlebotomy department at **GRO-B** Hospital in order to learn how to administer intravenous injections – she wanted to practice on others before doing it for me! In 1978, my mother had a needle stick injury while administering my Factor VIII products and subsequently developed HCV herself. She was ill for a short time but has since had no further complications.

18. Despite the lack of information provided to me regarding the infections, I was always happy with the care provided by Dr Goldman and Dr Lee. I had a long-term doctor patient relationship with them and they always made me feel comfortable during treatment. I think they were doing the best they could.

19. It is difficult to say what information my doctors should have provided to me. They should have provided me with all information known about the diseases, particularly in relation to transmission. I was aware it could be transmitted sexually but I didn't know much else.

20. I think medical care has come a long way since I was diagnosed with my infections and doctors would deliver the news differently these days. There is more of a focus on patient well-being than previously and you would likely be provided with information, brochures and counselling about the diseases.

Section 3. Other Infections

21. At around the same time I contracted HBV I also received the hepatitis A virus.

22. In 1987, I was told I had contracted delta virus or hepatitis D. This was discovered when I was hospitalised due to a low platelet count requiring me to have transfusions of platelets.

23. In the late 1990s or early 2000s I received a letter advising me that I am on the various Creutzfeldt-Jakob disease ("vCJD") registers as I had received blood products from a donor who later developed vCJD. When I received this news, I thought "great, another disease they've given me". It felt like I couldn't get a break.

Section 4. Consent

24. I do not believe that I was ever tested without my consent though I was not informed what my blood was being tested for. I'm actually quite happy for doctors to run routine tests in order to check for potential diseases and believe that it is good practice.

25. I regularly provided my consent to participate in trials for new blood products or medicines. I do not believe I was ever tested for the purposes of research without my

consent. Quite recently, I was involved in a Baxter Pharmaceuticals trial for a new Factor VIII product.

26. I cannot say whether my consent to being treated would have been impacted if I had known of the risks associated with the blood products. I was in a difficult position in that the treatment was necessary to prevent life-threatening bleeds. I think that even if I was told of the risks, I probably would have continued with the treatment.

Section 5. Impact

27. My infections have left me with a lack of energy and I tire very easily. I find that by mid-afternoon I have no energy left. I would often come home from work and fall asleep on the couch as soon as I sat down. I don't think I have finished watching a whole movie in a very long time.

28. I find that my health can be quite poorly and I am more susceptible to illness than I was previously. In 2006 I suffered from recurring chronic pains in my midriff and despite numerous MRIs and x-rays my doctors were unable to diagnose the source of the pain. I ended up having an emergency operation to have my gall bladder removed after my body went into toxic shock. I was in intensive care for three days followed by a week in the high dependency unit. I was off work for three months and looked after by my wife who was also at the time doing a full time teaching job. It transpired that my gall bladder had become gangrenous and infected. My doctors couldn't say that this was linked to my infections nor could they rule it out.

HCV Treatment

29. When I was diagnosed with HCV in 1976 there was no treatment available. To manage my HCV, my doctors monitored my bloods and liver function levels regularly. In 1987 my HCV infection flared up and I developed an issue with my platelets whereby the count was far too low. My doctors told me that my HCV needed treatment.

30. In 1987 I was referred to a hepatologist, Dr (later professor) Howard Thomas, at the Royal Free and who subsequently moved to St Mary's Hospital Paddington. Dr Thomas recommended that my HCV be treated with interferon, which involved intravenous injections every other day.

31. The interferon was a relatively new treatment at the time and I got the impression my doctors were still learning how it worked. Interferon has been likened to chemotherapy and in the days after the injections I would feel like I had the flu. I was constantly fatigued and would spend a lot of time on the sofa recovering.

32. After some months (I am unable to recall exactly how long) the interferon treatment was successful and my HCV was no longer detectable. However, I was treated with interferon for a total of seven years as my doctors were concerned how my body and liver would react if I were to stop treatment. The interferon was gradually withdrawn over a number of months and my reaction monitored until such time as I finally stopped treatment in 1994.

HIV Treatment

33. I started receiving treatment for HIV in 1997 when my viral load and other measures became worrying. The doctors decided they would start with antiretroviral drugs, which comprised of 3 different drugs that I took two to three times a day. I have changed my HIV treatment a number of times when new treatment options have become available.

34. My viral load is currently undetectable and I attend the Royal Free Hospital every six months for a check up. My HIV is currently treated with Triumeq, which involves taking one tablet once per day.

35. A physical side effect of the HIV medications has been lipodystrophy, which is a redistribution of my body fat. My body fat has largely been redistributed around my stomach, leaving me with a very thin face, legs and arms in proportion to my stomach, which is distended. I also experienced liver toxicity as a result of the HIV treatment.

36. I also suffered from severe diarrhoea with the first combination therapy which I had to control with drugs (Loperomide) until after a number of months I was moved to a less toxic combination of drugs. Subsequent therapies have not had this side effect.

Difficulties & Obstacles to Treatments

37. I don't consider there to have been any obstacles to the HIV and HCV treatments I have received. I believe the doctors were pro-active in offering the treatments, when

they became available. I do not consider (and am not aware) that there were any treatments which ought to have been made available to me but were not.

Impact of infections on other treatment/medical care

38. Following the closure of the dental department at the Royal Free Hospital a number of years ago, I attended a local dental surgery. I declared that I was HIV positive prior to treatment. Following this Mr GRO-B the dentist, would insist that my appointments occurred at the end of the day so that the instruments were not used on other patients. I remember thinking that he should be cleaning the dental instruments thoroughly between patients regardless of a patient's HIV status. The dental surgery was taken over last year and the current dentist doesn't have the same requirement.

39. I do not believe my infections have otherwise impacted my medical care or treatment options.

Impact on Private, Family and Social Life

40. I have not widely discussed my infections with my friends, family or colleagues. A few friends know about my HCV but I have never allowed the infection to rule my life. I found people didn't take much interest when I told them although now that the scandal is in the news perhaps people may take more of an interest.

41. As for my HIV infection, the only people who are aware of my status are my mother and my wife. I have never discussed my status with my friends or even my brother. I have not allowed the HIV infection to rule my life and I don't feel it is something that I should have to disclose to others.

42. My wife's family are aware that I have had health problems but we have never told them about my HIV infection. My wife's sister is a medical professional and we suspect she may be aware of the infections but she has never pried.

43. I have felt and continue to feel the stigmas associated with my infections. Part of the decision not to tell people about my HIV status is an awareness of the stigma associated with HIV. At the time of my diagnosis, there was a huge scare campaign in relation to HIV. People didn't understand the disease and were fearful of it. Another reason I don't discuss my infections is that I don't believe people need to know.

44. I am certain my infections and health problems have caused GRO-B considerable stress and strain. When we first started dating, I told GRO-B about my HIV status which probably weighed on her mind when deciding whether to pursue the relationship. My health issues definitely impact GRO-B and I find she is very protective of me.

45. When GRO-B and I decided to start a family we were referred to GRO-B, a social worker at the Royal Free Hospital. GRO-B raised a number of concerns about the risks of conceiving naturally which I'm sure caused stress to GRO-B. After trying briefly to conceive naturally, GRO-B and I made the decision to try IVF with donor sperm. At the time, sperm washing was not available or offered to us and we made the decision to use donor sperm. I know that GRO-B found the IVF process very difficult.

46. My mother is your typical mother and has always worried about my health. My mum is still alive, and although she is poorly and requires a lot of care and support. I know she worries about me but as long as I say everything is fine, she will my word for it.

<u>Impact on Education</u>

47. I was diagnosed with HIV in 1985, although they could trace my infection back to early 1980 (using stored samples) the same year I was sitting my A-Level examinations. At the time, I was experiencing a lot of fatigue and tiredness and I ended up doing pretty poorly in my examinations. My haemophilia meant that I missed a lot of classes in primary school and high school (at least a third). At school, I wasn't allowed to play any sports or run around at lunchtime and I was made to sit indoors with one of my friends. I was never allowed to study woodwork or subjects which carried a risk of injury.

<u>Impact on Work</u>

48. I worked as a civil servant until April 2018 when I made the decision to retire. Throughout my career, I suffered from tiredness and fatigue, side effects of my infections and treatments, which I believe limited me in terms of career opportunities. By the end of a workday I was often so exhausted I had little energy to do anything other than go home and rest.

49. I think that an awareness of my health limitations prevented me from applying for promotions or taking career risks that I otherwise may have taken. I was always aware of the effect that stress had on my health and in particular causing a bleed.

50. My workplace understood my health issues and was quite accommodating. I had to declare my HCV and HIV infections when I applied for the civil service but information never filtered down to the line management. My workplace would allow me to take time off for medical appointments, take long periods of leave related to health and work from home. I did make line management aware of my haemophilia and HCV status.

Financial Effects

51. Despite my infections, I have been able to have a career and continue working up until quite recently. There have been occasions where I have had to take extended leave from work due to health issues and this has a financial effect on my family. My family has never led an extravagant lifestyle and money is something we have always been conscious of.

52. The IVF treatments were incredibly expensive and caused considerable financial stress to GRO-B and I.

Section 6. Treatment/Care/Support

53. I don't recall being offered counselling or support immediately after my HCV or HIV diagnoses. At one stage, the Royal Free Hospital referred me to a support counsellor, GRO-B, who provided general support. When GRO-B and I saw GRO-B on a few occasions when we were trying to conceive.

54. I am not sure that I would have taken up counselling services if they had been offered to me at the time of my diagnoses.

Section 7. Financial Assistance

Macfarlane Trust

55. I became aware of the Macfarlane Trust in the early 1990s when they contacted me as part of a Haemophilia Society reach out program. As far as I can recall, the application process was rather straightforward and involved filling out a number of forms. I did not have to supply medical records, just a letter from my doctors confirming my infections.

56. I recall the Macfarlane Trust had a payment scale whereby you received certain amounts depending on whether you were single, married or married with children. Prior to receiving payments, I had to sign a waiver stating I would not pursue litigation.

57. Around 1992, I received a payment of £30,000, which I put towards the mortgage. I could also apply for discretionary payments to cover the cost of things such as the deposit for a Motability car, new mattresses and household repairs.

58. When GRO-B and I were going through the IVF process, Dr Christine Lee suggested we contact the Macfarlane Trust and ask for financial assistance. The IVF process was hugely expensive and cost over £10,000 per cycle. Dr Lee wrote to the Macfarlane Trust on our behalf and the Trust seemingly grudgingly agreed to provide £1,000 towards the IVF. It was a small amount of money in comparison to the overall cost.

Skipton Fund

59. Like the Macfarlane Trust, the process of applying for the Skipton fund was not difficult as they approached me and asked for the details confirming my eligibility. I don't recall having to sign a waiver against litigation to be eligible for the funding. I think the initial Skipton payment was approximately £15,000.

60. The Skipton Fund also made regular monthly payments but I don't recall the exact amounts.

EIBSS

61. I became aware of the EIBSS in late 2018 when they contacted me to say they would be taking over the financial assistance programs. Again, the application process was not difficult and I was told I was entitled to stage 1 payments. The payments are

approximately £1,500 per month for the HIV and £333.33 per month for the HCV infection.

62. At the time the EIBSS was established I did not apply for stage 2 payments, which I did not think I qualified for. I later received a letter from the EIBSS stating I was eligible for stage 2 payments and suggesting that I apply. I am currently going through that process.

63. In reference to EIBSS, the process for applying for stage 1 happened automatically. I was put off from applying for stage 2 due to the criteria, which I did not think I qualified for. However, a letter was written asking why I had not applied so I did the application.

Observations about the Schemes

64. I find the EIBSS more difficult to engage with than the Macfarlane Trust. For example, in order to be given a grant for a bed or other costs, it is necessary to provide letters from doctors and a number of quotes. It is overly bureaucratic compared to the Macfarlane Trust.

65. In comparison to the Macfarlane Trust, the EIBSS feels more distant. It is not an automated process but you are dealing with civil servants who seem somewhat removed from what you are going through. It would be nicer to engage with workers face to face rather than over the phone.

66. The MacFarlane Trust regularly funded events such as weekends away and wellbeing conferences for those infected and their family. These were great as they allowed you to connect with people in similar situations. As far as I am aware, the EIBSS does not offer the same services.

67. The level of financial assistance that I received from the various funds, have been a nice addition to my regular income, but I don't think the payments are sufficient for those who have lost careers, loved ones or their own lives.

68. I think the payments should be labelled 'compensation' rather than 'ex-gratia'. I would also prefer a one-off payment, rather than monthly amounts. I would like the government to calculate how much I would receive if I lived until 80 and provide a one-off payment rather than drip-feeding me the payments.

Section 8. Other Issues

69. I have not previously been engaged with any campaigning or litigation in relation to the infected blood scandal.

70. I would like the Inquiry to answer the following questions:

    i. Why did documents go missing?
    ii. Why was self-sufficiency for blood/ blood products not achieved?
    iii. Why were pleas to become self-sufficient brushed aside?

Statement of Truth

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

Signed GRO-B

Dated 21-05-19