ANONYMOUS
Witness Name: GRO-B
Statement No.: WITN5405001
Exhibits: Nil.
Dated: 08/04/2021.

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 01 March 2021

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1962 and I reside in Middlesex, and my full address is known to the Inquiry.

2. I am married and have two children; a daughter aged 18, and a son aged 32.

3. I was born in India and came to the UK in January 1968. It was not until I arrived in the UK that I was diagnosed with Haemophilia A, which initially was not detected by doctors in India. My mother always knew something was wrong with me because I bruised easily, but at the time, she was not sure what was wrong with me. I am now aware that a great grandparent

on my mother's side had Haemophilia and two of my mum's cousins also carry the gene.

4. I intend to speak about my infection with hepatitis C (HCV) and HIV infection, which I contracted from Factor VIII blood products. In particular, the nature of these illnesses, how they have affected me, the treatment received and the impact it had on me and my family.

5. I can confirm I am not legally represented and I am happy for the Inquiry Team to assist with my statement.

Section 2. How Infected

6. My father came to the UK with a British passport and settled in GRO-B sometime in the mid 1960's and in January 1968 invited me and the rest of my family to join him in GRO-B Soon after starting primary school in GRO-B I was involved in a car accident; I ran across a zebra crossing, naively unaware that you needed to wait for the cars to stop before crossing the road. I was rushed to Manchester Children's Hospital in Pendlebury and this is where I was diagnosed with severe Haemophilia A. Dr Evans (Haemophilia Consultant) informed my parents that my blood clotting Factor VIII was 0% and that I would require blood transfusions.

7. Up to the time before my road accident (aged 5 years old) I do not recall receiving any treatment for what I now know as my bleeding disorder, Haemophilia A. I received a blood transfusion on two occasions; the first time in 1968 following the car accident and the second time, in late 1969 when where I knocked my left knee on a school table.

8. In January 1971 my youngest sister was born and on a home visit in February a midwife questioned my mother why I was not at school. My mother responded due to a bleed in the knee I was not able to go to school. This resulted in the Local Authority arranging for me to go to boarding school in May 1971. The school itself was called GRO-B

GRO-B now known as GRO-B GRO-B based in GRO-B The Boarding school was about 40 miles from GRO-B

9. The school was not specialised to treat Haemophilia, but it offered schooling and medical supervision, which meant if I had a bleed and needed medical attention, I could not escape my educational requirements.

10. Whilst I was at school I suffered from many spontaneous and trauma bleeds. These bleeds resulted in me being sent to GRO-B GRO-B to be treated with Cryoprecipitate. I was under the care of Dr Martin. I thought that Cryoprecipitate was a wonderful treatment for bleeds, but unfortunately, I was allergic to the product. Due to the allergy I had to have Piriton administered before Cryoprecipitate. During school holidays, I was treated at The Manchester Children's Hospital.

11. From 1978 onwards, I was given a Factor VIII concentrate called Hemofil, known to be imported from the USA. It was treatment on demand and at age 14/15 I was able to treat myself intravenously. At the time, I thought it was wonderful as I didn't react to the product In the final year of my schooling 1978/79, during school term, I received Cryoprecipitate from GRO-B and during the school holidays I would pick up supplies of Factor VIII concentrate from Manchester Children's Hospital.

12. On my second visit to pick up home supplies, I remember Dr Evans informing me that the next product he would give me was British made and is just as good. He told me this is what has been supplied by the Health Authority. I was never warned of any risks associated with using the product. Now knowing the truth, I do believe I should have been made aware of the risks that went with administering such products, given that it was well known in the early 1970s that these products were likely to transmit viruses.

13. At the age of 18, my care was transferred to Manchester Royal Infirmary and there I continued to receive Factor VIII concentrates from different companies.

14. In 1984, I moved to London and my care was transferred to Dr Tuddenham and Dr Kernoff at the Royal Free Hospital. It was then, I started to become aware through media channels that Haemophiliacs were at risk of AIDS and other viruses, which made me think that I may have been infected.

15. I had no symptoms of HIV or HCV, but it was not until 1986 that I became aware of my HIV positive status and not until, 1990/1991 that I was made aware of my HCV results.

Section 3. Other Infections

16. In 1999 I received a letter about vCJD, which informed me I had received a batch of Factor VIII product that contained it. Aside from vCJD, I do not believe I was infected with any other diseases as a result of the Factor treatments I received.

Section 4. Consent

17. When I used to attend Manchester Children's Hospital I was accompanied by my parents. Whilst at Boarding school, I was accompanied by a member of staff from boarding school. At the age of 18, I started attending Manchester Royal Infirmary on my own. I don't recall consent being asked at any time until I came to London. I trusted the Health Authorities and that they were doing the right thing for me. The only consent I remember signing is to register at the Royal Free Hospital and have my records transferred from Manchester Royal Infirmary.

18. Even whilst I was at the Royal Free, I trusted the Doctors' and the Health Authority to treat me. There was never a conversation regarding consent until mid 1990's.

Section 5. Impact

19. In 1983 I was attending Manchester Royal Infirmary and whilst I was waiting to be seen by the consultant, a patient mentioned in passing, "*Do you know that these products contain AIDS*". Initially I was quite taken back, and naively responded, "*What's AIDS*". The passing patient briefly explained what Aids is and I thought to myself that Doctors and Health Authorities would never prescribe infected products. From this point onwards, I believe I knew the products I had been given may have contained HIV, but I put it to the back of my mind and tried to ignore it.

20. My general attitude was to keep things quiet and not to tell anybody about my inkling that I may have been infected.

21. From finishing Boarding school and moving to London, I was in relatively good health, aside from the mental anguish I endured from not knowing whether or not I had been infected. It was not until 1986 that I became aware of my HIV status whilst under the care of the Royal Free Hospital.

22. Once I moved to London, I was fortunate enough to obtain employment at a Benefits Agency, and then moved to Barnet Council and thereafter found a job at GRO-B Council, as a Housing Benefit Officer. I had no issues in disclosing my Haemophilia, and that did not seem to cause any problems, but following the release of the Panorama program in and around 1988, a member of my Colleagues at GRO-B Council questioned me in front of all the staff and asked me specific questions about whether I had caught certain diseases from blood products. Fortunately, my Manager was listening and knew that was wrong for me to be questioned openly in front

on many staff in an open plan office. My Manager put a stop to this and threatened the individual with dismissal, which made it easier for me to carry on working there.

23. Despite ~~his~~ her efforts, it was still difficult for several months for me to focus at work as I kept everything to myself and I found it much harder to work there. However, I stayed put in my job at GRO-B Council. I felt restricted in my opportunities, however I felt secure at GRO-B Council and didn't look to moving on as I didn't want to have to confront this type of situation again.

24. GRO-B Council have been supportive and have not had any issues with sickness leave, although I rarely take time off as sick ~~pay~~. I would rather avoid potential questions by colleagues as to why I am not in the office. I usually take my annual leave when I need to attend any hospital appointments.

25. It is difficult to keep everything a secret, because people are always so curious why I had both knee replaced at a young age, I was questioned by colleagues on how I got listed so quickly, I would say that I had severe Arthritis and move away quickly to avoid further question.

26. Whilst I was grateful for my job with the Local Authority, when I was young I had ambitions of becoming an Electronics Engineer and I managed to obtain my qualifications in the late 70's and early 80's, however I have no job to show for it. I undertook four years of City and Guild courses in electronic servicing and computer programming and processing. I submitted lots of applications in which I had to declare my illnesses; I was unsuccessful in all of them. I am unsure if this was because of my HIV status, but it does come to mind.

27. Before I met my wife and prior to our marriage in 1986, I decided not to tell her about my HIV. We were introduced by family member. As I was scared that it might be my only opportunity to find a partner and marry, I decided

not to tell her about HIV. She originally spoke with a friend about my Haemophilia, who re-assured her it was nothing to worry about, but obviously at this time she knew nothing about HIV. Fortunately, my wife has not been infected, but telling her the truth about my health a few weeks after we married did impact on our relationship in many ways. I also feel immense guilt for keeping this a secret before we married; it constantly plays on my mind, and I imagine it will for the rest of my life.

28. It was also very challenging to become aware of my HCV status in 1991/1992, as this was yet another disclosure I had to make, to my wife. The burden felt never-ending and relentless.

29. I know it affected the intimacy of our relationship and this impacted on her greatly. At the beginning, we didn't think about having children as my wife feared the risk of me infecting her and the potential risk of it being passed on to the children. It was a great relief to know that I didn't infect my wife.

30. My wife used to speak to Riva, a counsellor at the Royal Free Hospital Haemophilia Centre, to discuss her concerns about getting pregnant. We were given options about sperm washing, but chose to conceive naturally.

31. When our son was born, my wife was extremely concerned about whether diseases could be passed on through breastfeeding. It was difficult for her as there was little knowledge on this at the time. In the end my wife decided to avoid breastfeeding altogether. She experienced a lot of pressure from my mother about the reasons she wasn't breastfeeding, and not being real mother I know this caused my wife great distress. Our excuse was always centred on financial difficulties and that my wife would need to go back to work soon after the birth, as we could not afford her taking maternity leave.

32. I was extremely blessed to have been given a healthy son and I was not eager to have another child. There was always a concern that we might have a girl, which would mean the Haemophilia gene would be passed on; I wanted to avoid this at all costs given what had happened to me. Despite

this, we decided to have another child. My wife and I were blessed with another child, a girl, but unfortunately, my daughter is a carrier of the Haemophilia gene.

33. We were both very worried about the chance that through childbirth our children may have been infected; when the babies were born, we asked the Royal Free to test them for HIV, which fortunately both tests came back negative.

34. Once our children were old enough, we told them about my Haemophilia, especially as my daughter needed to understand the implications of being a carrier. Aside from this, our children were able to live relatively normal lives, but my wife had to take responsibility for most things; she always took them to school or sporting activities. Sadly, I could never play sports with my son.

35. At home I constantly worry about contamination; I avoid DIY tasks, as it is very easy to injure myself and increase the risk of infecting my family. If I cut myself, I immediately apply a bandage and wipe down the surfaces with anti-bacterial products. I told my son not to use my razor and told both my children to not share toothbrushes, which I attributed to good hygiene practices. Both my wife and I decided not to tell my son about my conditions until 2013. My son now knows all the details about my health, but he has not yet disclosed to his wife about the full extent of my health, except that I have Haemophilia. We have decided to let him tell her. Our daughter is still unaware about the full extent of my health and I don't intend telling her about my HIV status until it is necessary.

36. My wife and I kept my HIV and HCV status a secret from most of our families, including our children and our parents. Both of my parents are not educated and do not have a good command of the English language, so it was easy to keep my HIV and HCV illnesses sheltered from their knowledge. I told my sisters about HIV and HCV in the mid 1990's, and they treated me just the same. My wife's family only knows that I have Haemophilia.

37. Before my Niece's (sister's daughter) wedding, whilst assisting with the cooking, my wife slightly cut her finger, and a comment was made by a family member in front of lots of people "we don't want aids". This hurt my wife very much as whichever family member had put Haemophilia and HIV together had decided to make a very cruel remark.

38. Physically I suffer with bad pains all over my body and questions have been asked at work about my use of strong painkillers, such as Codeine, and Tramadol. As I mentioned earlier, for a period of time I believe I knew I had been infected with HIV, but had no confirmation of this. In general, I had no ill effects from HIV, but I felt noticeably more lethargic and tired.

39. Similarly, I had no symptoms of HCV until the late 90s, early 2000s. This also made me feel quite lethargic and I noticed increased fatigue, but I assumed it was caused by the painkillers I was taking for joint pains. From thereon, the symptoms became more apparent; I suffered with constant headaches, brain fog, and lack of concentration.

40. I was prescribed Amitriptyline for the significant amount of pain I was experiencing, which made me extremely tired, and incapable of doing anything in the evenings.

41. I had two rounds of treatment for HCV; the first course of Interferon alone I had severe side effects, such as shivers, headaches, flu like symptoms, and depression. I was able to reduce my HCV viral load to 20%, but it became virtually impossible to reduce it any further. Despite this, I still had to endure the treatment for another four months, and yet, it was unsuccessful. The second course was a combination of Interferon with Ribavirin. I had same severe side effects and I managed most of the symptoms with pain killers throughout the course which allowed me to go to work. Again the combination treatment was unsuccessful.

42. At times my depression led me to have suicidal thoughts, but I often talked myself out of it. I was offered counselling or support from healthcare

professionals to help deal with my mental health problems, but I never accepted as I felt this will not achieve anything.

43. In terms of finances, I struggled to apply for a mortgage. When I first moved to London, I was living with my cousin and his wife in GRO-B and they knew about my Haemophilia but nothing else. His wife worked for a building society, but I did not make the first application for the mortgage through the building society she worked for. My first mortgage application was without anyone's assistance and was rejected. I believed this was due to my health status. However, I did not ask the Building Society for their reasons. I then sought advice from my Cousins Wife and this meant I had to disclose my health conditions. She said to me that if I took out an Endowment Policy in my wife's name, she can push the application through, otherwise it will be rejected due to my health status. My application for the mortgage was accepted with an Endowment policy in my Wife's name. But later I felt the atmosphere was uncomfortable with my Cousin, and I could not wait to move out to our own home.

44. Holidays were very rare due to finances but when I could afford one, I struggled to obtain holiday insurance, as they often turned down Haemophiliacs with HIV. If I could find one in the limited pool of companies that would insure me, it would always cost more than the holiday itself. A few times I have gone on holiday without insurance and just accepted the risk that it carried.

45. Whenever we did travel, I took my Factor products with me and had a letter from the hospital to explain why I was travelling with them.

Section 6. Treatment/Care/Support

46. It is hard for me to reconcile that at age 14/15 I was delighted to have received Factor VIII products and be able to treat myself. If I knew the risks and ultimately the consequences, I would have considered taking

Cryoprecipitate for the rest of my life and never opted to take the Concentrated Factor VIII products.

47. During the period of 1978 to 1984 I know I was given products produced by Armour, Baxter, and Cutter, and these were provided to me from Manchester Pendlebury Children's Hospital and Manchester Royal Infirmary. I knew the above products where imported from USA and I very rarely had British (BPL) products as I was led to believe they were costly, and there were some supply issues. I believe that the Health Authorities and the Companies fully well knew the risks with these contaminated blood products, but they still continued to provide them.

48. After I moved to London in 1984 and before I got married in 1986, I believe the Royal Free Hospital tested me without consent, as they offered me HIV test results and I was completely unaware that they tested me in the first place. I was totally in denial and didn't want confirmation of something I already had an inkling about. I believe they began testing everyone without permission, as they oddly offered me a Hepatitis B vaccination and a booster a few years later. I took the vaccine and booster.

49. I was not tested for HCV until 1990/1991, and it was not until few years later in and around 1993, that I was offered Interferon treatment. This is when I began to question the treatment I had received as they tested me for HIV without my consent in the late 80s, and surprisingly did not disclose my HCV status for another three years.

50. When the Royal Free Hospital offered me HCV treatment they informed me that it does not always work and it totally depended on the type of Hep C virus I endured eight out of the prescribed twelve months of treatment, only partially reducing my viral load to 20%. Supposedly the Doctors' knew my viral load was at 20% four months in, but still told me to persevere for another four months. As I mentioned previously, the side effects were horrific. Every Interferon injections gave me shivers, headaches and fever like symptoms, and made it difficult for me to concentrate.

51. As I could not reduce my viral load below 20%, I attempted a second course of treatment in 2002/2003 of combined Interferon and Ribavirin. I managed six to seven months of the twelve-month course, and once again, it failed me.

52. I agreed to a liver biopsy (Transjugular) in 2007 and there was nothing significant mentioned about the condition of my liver. I assumed this meant that it was ok, but after several discussions with my Doctors', it was clear that they suspected there was some damage (Cirrhosis).

53. Fortunately, in September 2015 I managed to clear the virus with a course of HCV treatment combined with anti-viral medication. I now have six monthly reviews for blood tests and check-ups at the Ian Charleson Centre clinic to monitor my HIV and the damage to my liver. I have also had a few fibro scans of which the result have fluctuated and I have been informed that I am likely have some Cirrhosis of the liver.

54. In relation to my HIV, I received no treatment until 2015, and I was happy to go along without treatment, as I was informed that my CD4 count was surprisingly high and this meant the HIV was not affecting my health that significantly. I did agree to take part in a three-year Concorde trial in early 1990 at the Royal Free hospital, which included a mix of placebo and AZT patients. I am now aware that I received the placebo.

Section 7. Financial Assistance

55. I became aware of the Skipton Fund through The Haemophilia Society, which informed me about many other haemophilia related topics, such as heat-treated products.

56. Soon after my daughter was born, I decided to apply in 2004 for the first stage payment, which I was successful in obtaining. I don't recall having any difficulties in the application process.

57. The second stage payment required a higher threshold to meet, which necessitated a certain level to reach in your fibro scan tests. I sent the form to the Royal Free Hospital and Dr Thynn Thynn Yee refused to fill in the details, as my fibro scan did not reach the required level. As a result, I never submitted the application form.

58. In 2016 I had my left knee replacement, when at the same time Theresa May released the special mechanism payment scheme. I decided to apply in 2017 with the supporting statement of my Doctor from the Royal Free, and I continue to receive this payment to this day.

59. In addition to the above support, I am also in receipt of payments from the Macfarlane Trust. In 1990, I accepted the offer from the government via the Macfarlane Trust a lump sum payment on the condition that I signed a waiver absolving my right to take legal action. At the time, I was in financial debt and was concerned about how I would meet my second year of mortgage payments, so I had no option other than to sign the waiver.

60. I recall the monthly payments increased after the Archer Inquiry in 2009.

61. I used to worry greatly that if I passed away, I would leave my wife with a debt that she could not repay. I am happy to say that I have now cleared all the debt I incurred over the years, and am able to help my son to buy a property.

Section 8. Other Issues

62. My intention was not to pursue accountability for what happened to me for the money, but to identify who is at fault and why they did not answer these questions at the time, nor acknowledge the information that was coming to light about the transmission of viruses through blood products.

63. I do have questions on the David Owen documents regarding the budgets, which went missing and subsequently have been found to be destroyed.

64. I do not understand why this saga went on for so long, despite the developing awareness and knowledge about the contamination of blood products. Looking back, I believe the government paid out a lump sum early on and made us sign a waiver to give them time to shred documents

Statement of Truth

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

Signed GRO-B

Dated 08/04/2021