Witness Name: GRO-B
(Anonymous)
Statement No.: WITN53540001
Exhibits: Nil.
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B (ANONYMOUS)

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 21 February 2021

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1959 and I reside in GRO-B and my full address is known to the Inquiry.

2. I have been married to GRO-B for 20 years and we don't have any children. As of December 2020, I took early retirement, but prior to this I ran a team of project and technology managers in the broadcast and media industry. I was employed by the BBC for 25 years before my department was outsourced to Siemens and then later Atos, a big global IT out source company based in France. I was fortunate to travel with work and undertook some projects in South Africa and across Europe.

3. I was born with a hereditary condition called Haemophilia A, which initially was not detected by doctors; I was what referred to as a blue baby at birth. At 18 months I was diagnosed, whereupon both my brothers were also tested, and found not to suffer from haemophilia.

4. I intend to speak about my infection with hepatitis C (HCV) and HIV infection, which I contracted from Factor VIII blood products at St Thomas' Haemophilia Centre. 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. I was born in GRO-B Sussex, where I had no access to treatment as it was a considerable distance from any major hospital. Most of the time I persevered with swollen and damaged joints. I was on occasion admitted to Eastbourne hospital due to recurring teeth bleedng and had both cryoprecipitate and Factor VIII treatment.

7. I was also home schooled until aged 11 because the educational authority in East Sussex wouldn't allow me to go to primary or secondary school , as they felt they couldn't look after me properly. It was obvious that they were too nervous to look after a child with haemophilia, but instead recommended I boarded at Lord Mayor Treloars College from aged 11.

8. My parents and I visited the college in Hampshire, where I was shown around and given a prospectus. We decided it would be a much better environment for me, because I could obtain proper schooling and treatment for my haemophilia.

9. Soon after this I joined Lord Mayor Treloars College from the age of 11 to around 19 years, where I undertook a practical City and Guilds course in my last two years. Whenever I experienced a bleed at college, I was treated at the college itself or at the local Treloars Hospital in Alton. Most of my time there was spent at the Boy's school in Upper Froyle some 3 miles from the Town of Alton. Once I turned 15, I remember moving to a Jacobean Mansion, part of the school estate, which was very nice and I now believe is a hotel.

10. I do not believe I was infected whilst at Lord Mayor Treloar's College; I received blood products and had regular blood tests, but nothing was ever detected and certainly HCV, nor HIV was ever mentioned.

11. After I finished my schooling I attended College in London at GRO-B GRO-B I was then successful in an application to become a Broadcast Engineer / Operator for the BBC. I moved to London and registered at St Thomas' Haemophilia Centre (HC) since moving to London for College and work. This is where I believe I contracted HIV and HCV. This was confirmed to me, as I believe the team at St Thomas' traced the contaminated Factor products that were administered in my treatment whilst registered at their centre.

Section 3. Other Infections

12. I was also infected with hepatitis B and informed there was a risk I may have been infected with vCJD. Aside from these I am not aware I was infected with any other viruses from blood products.

13. I did acquire another infection: Hepatitis E, whilst I was on holiday in Spain for a GP Formula One weekend due to a lack of hygiene in a restaurant.

Section 4. Consent

14. There was never really an issue with consent, as I believe I was given what treatment was available via the NHS and the government selection of suppliers, which ultimately, I needed.

Section 5. Impact

15. It was difficult for me as a child, because I was different to everyone else; my brothers went to school and I had home schooling. Socially at that time it was not acceptable for those with disabilities to mix with other children in 'normal' schools. Ultimately, they would not have known how to deal with me and my haemophilia, but it still magnified my awareness of being different. My parents did their best in supporting me whilst I was at home, and I believe they benefited from being members of the Haemophilia Society, as they published advice for families caring for haemophiliacs.

16. When we became aware of Lord Mayor Treloar's college, my parents thought it prudent to send me to the boarding school to obtain a reasonable education and be surrounded by other children who were of the same age. Whilst I knew there would be better educational facilities, my parents were unable to visit regularly, as the trip from Sussex to Hampshire was a fair few hours and the traffic was awful. Despite this, it was an improvement from what I had come from.

17. After I left Treloar College, and as I mentioned earlier, I moved to London to start at a London College and my work career and registered at St Thomas' hospital HC. It was there that I became aware of my HIV infection in the first instance, and the HCV infection later on.

18. Once I became aware of my HIV positive status, I chose not to share it with anybody, not even colleagues at work. I would say I have always tried to fit in, so I never made a big deal of it; I just kept it to myself. By the time I became aware of my HIV status, my father had died and I didn't see the point in sharing it with my mother. There is nothing she could have done, so I carried the burden alone.

19. Before I came to know about my HIV, I wanted to get married and potentially have children. This changed quite dramatically upon finding out my diagnosis and I actively avoided relationships, because I didn't want to pass it on, but also as I did not feel comfortable divulging the information.

20. When I met my wife, it took some time for me to feel comfortable to explain my situation and I was also lucky that she was agreeable to a decision that meant we would not have children.

21. My perception was that HIV was not understood at the time, and elements of the media perpetuated a fear surrounding the disease. There were lots of socially unaccepted associations with it, and people were not knowledgeable on the subject. This made it even more difficult for me to come to accept my situation, and left me with a guilty, burdensome secret. Even to this day, I do not advertise my infection status.

22. When I found out about my HCV, sometime after the HIV diagnosis, I began treatment as soon as it was made available to me. I did feel fatigued, but cannot say it was out of the ordinary, as I always felt tired due to my haemophilia.

23. My skin noticeably got drier and I experienced a collection of other side effects, but I just kept going; I had lived a life of continual treatment and constant knocks and bruises. I was already burdened with hardships, so it was just another day.

24. More recently the team at St Thomas' has been monitoring my liver and I have regular ultrasound and fibro scans, which have shown scarring on my liver. I am under the impression that there is no further scarring, and the condition of my liver remains relatively consistent. The St Thomas's Team continue to supply medical support.

25. Throughout the time I was undergoing treatment, I was still working at the BBC and I suppose the backdrop of what was happening in my personal life made it all the more difficult to progress in my career. I was used to

living with such a complex and permanent health condition, and I guess that conditioned me to push through these other additional bits.

26. In any event, during my mid-20s to mid-30s, I was not able to commit my full attention to my work and I do believe this impacted the progression of my career. There was one specific opportunity, where I could have gone to Canada, but I didn't take it because I was concerned about my physical health and I feared the chance that I would need to expose my situation to others; I always took the safer option.

27. I am now in a position, where I have been able to retire early. However, I do have a sense that had I not been burdened with HIV and HCV as a result of the blood products I received as a young man to treat my haemophilia, I would have been in a much more comfortable financial situation, and arguably better off in my retirement. Decisions I made in my career have clearly affected the speed in which my career progressed and further impacted my life after work.

28. I feel as if decisions I made in the last 40 years of my career have now impacted me in my later life. In some respects, I was quite lucky, because the work environment at the BBC and in my specific team was very accepting, and despite not sharing what had happened to me with anybody at work. I felt my colleagues were a fairly open, tolerable, and accepting group of people.

29. I had to take time off for my knee replacements and I continued to work during my hip replacement, despite being physically unwell, I soldiered on and continued to work. There were times when I would need to leave work to attend hospital appointments for recurring tests and it was never an issue for my career.

30. As I briefly mentioned earlier in my statement, as a haemophiliac I often experienced stigma associated with the condition, as it is well known now, that most haemophiliacs were infected with either HIV or HCV, or both. These diseases were also linked with homosexuality and their lifestyles

were often dragged over the coals. In any case, this made it much harder for me to come to terms with my fate, and it is a huge burden to have carried for all these years.

31. I am sure my wife has been impacted too, as she has been unable to share the details of our life with anybody else.

32. It must have been difficult for my parents and I would imagine they feel responsible in some respects, given that my mother was a carrier and there were no tests at the time.

33. Neither of my brothers were affected, and I am still in touch with one of them, but the other has not kept in contact. I am the youngest, so they both knew I had haemophilia since birth and have treated me much the same, but I have not divulged all the details of what's happened to me since.

34. I went through very low periods, which was due to a mix of a non-existent social and home life, and also as a result of my HCV treatment; it really was not a very pleasant time.

35. Above all, I do continue to worry about whether I will inevitably develop a major liver problem later in life. I'm hoping this won't be the case, but you never know; the full life cycle of this has not reared its ugly head just yet.

Section 6. Treatment/Care/Support

36. At Lord Mayor Treloars College, I was classed as having severe haemophilia, but was very lucky in that I only needed treatment infrequently. I only received treatment on demand, never prophylactically. I had a very pleasant time at Treloars; I don't recall any bad memories from my time there. I was able to enjoy a variety of sports there, such as swimming, football, and cricket.

37. Whilst I was at college, I didn't suffer from long term joint problems. This only started to take a toll on my body in the years after, where I had to have two knee operations one a replacement plus a hip replacement. Fortunately, all were successful operations.

38. Throughout most of my treatment I was never advised of the risks associated with the use of Factor products, as I mentioned earlier, I was given what was available at the time. I was only told much later that there were heat treated products, but was advised that there was not much point in me using them, as I was already infected. In hindsight I do think I should have been made aware about the risks involved, but I needed treatment and safer options were not available at the time.

39. I can remember overhearing conversations at St Thomas' about the financial decisions made to go with the less safe blood products, and it was rife in the press at the time. I am unsure when exactly this was, but I was between 20-30 years old.

40. I attended St Thomas' hospital for regular appointments, where I often bumped into boys from Treloar's college. We talked about others who were at the college and what they were doing. I soon became aware that there were a significant number of boys who had not done very well and had passed away since being at college. They tended to be severe haemophiliacs, or had arrived at the college just after I left at age 18.

41. My 12-month course of HCV treatment (Interferon and Ribavirin) worked reasonably well and I successfully cleared the virus. During this year I had to go into hospital regularly for tests as a result of the side effects I was experiencing. I learnt to inject myself at home, and had support from a specialised nurse called Jenna who was very helpful and thorough. My understanding is that they only told me about the HCV, when they knew this treatment was available.

42. I am on continuous medication for HIV, which has been monitored under the care of Ranjababu Kulasegaram at St Thomas' Hospital HIV clinic. I also see Dr Docherty at St Thomas', but have not seen him as often due to the coronavirus pandemic and national lockdown.

43. As far as I can recall, I was not offered psychological or counselling support. In any event, I am unsure if I would have taken up the offer.

44. As mentioned at paragraph 12, I received a letter regarding my at-risk status of vCJD. I thought this was rather strange, but it did make me question whether I was going mad. I was concerned, and this concern was not alleviated by the letter. It provided little, if any information about what vCJD is, nor any insight on whether I could be tested; I felt my only option was to wait and see.

45. I have not had issues accessing other treatments, however I opted to use the dentistry services at St Thomas' hospital rather than registering at a private practice. I knew I would need to disclose my HCV and HIV status and preferred to avoid that eventuality.

Section 7. Financial Assistance

46. I came to know about the Skipton fund through my health care professionals at St Thomas' hospital and they suggested I applied for compensation. In 2004 I decided to apply and found the application process reasonably easy to follow. The team at St Thomas' assisted me in applying and were quite forward thinking about the scheme. In fact, they supplied all the medical references and sourced the infected batch numbers of Factor products I had received in my treatment.

47. Shortly after I submitted the application, I received a letter informing me that I was successful and that I would receive a one-off payment, and quarterly payments from thereon.

48. It is difficult to say whether the amount I received was sufficient, especially as I have opted for early retirement and it would be useful if it was a little bit more. Nevertheless, it will certainly not compensate for the choices I had to make during my career.

Section 8. Other Issues

49. It is only in more recent years that I have been able to afford comprehensive holiday insurance. In the past it was very difficult for me to obtain full coverage. Given all my conditions, it was always considerably more expensive.

50. I also have a mortgage and at the time I acquired it I withheld information about my HIV and HCV status, as I would never have obtained one had I disclosed the truth. The problems would have been immense, if I had disclosed such information. During the last 25 years, I ran the risk of the truth being unveiled.

Statement of Truth

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

GRO-B

Signed ____________________

Dated 17/3/2021