Witness Name: GRO-B
Statement No: WITN7208001
Exhibits: nil
Dated: 4th November 2022

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 30 August 2022.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1949 and my full address is known to the Inquiry. I am retired and have two grown up daughters.

2. I intend to speak about my late brother GRO-B: B who was born on GRO-B 1961 and sadly passed away on GRO-B 1994, at the age of 33. He was infected with HIV and Hepatitis C (HCV), as a result of receiving contaminated blood products to treat haemophilia. In particular, I will describe how he had learnt about his infection, how his illness had affected him, me and our family thereafter.

3. I can confirm that I have chosen not to have legal representation and that the Inquiry Investigator has explained the anonymity process to me. I wish to be anonymous.

4. My sister, GRO-B assists me with my statement. Her date of birth is GRO-B 1951 and she is a widowed pensioner.

5. I wish to acknowledge that naturally as time passes, memories can fade. It is very difficult to remember events from 30-40 years ago, but we have been able to provide approximate timeframes for matters based on life events. However, these timeframes should be accepted as 'near to' rather than precise dates. We have constructed this statement without access to my brother's medical records.

Section 2. How Affected

6. Our brother, B had severe Haemophilia A. As a baby he would bruise very easily and once he started crawling and banging into things, he would come up in huge swelling in addition to the bruising. B underwent a lot of tests but without any family history of haemophilia, doctors initially presumed that he had leukaemia. He was 10 months old when it was confirmed that he had severe Haemophilia A.

7. We had no history of haemophilia in the family because our mother had a sister and although our maternal grandmother (who was born in 1908) had 11 brothers, 4 of them died very young and we are unaware if any of them were diagnosed with haemophilia. We cannot trace our family back beyond our grandmother – her mother was Spanish and her father was French.

8. Throughout his childhood, B was always in hospital. My sister and I would often wake up in the morning to find that our mother had gone off in the night to accompany B into hospital, which could be Margate, Hammersmith or even Oxford. Sometimes she would be gone for up to a month, depending on the severity of the bleed. He was never given Factor VIII injections until he

actually had a bleed, so he consequently ended up with a lot of problems – especially with one particular knee which never seemed right and he always walked with a limp.

9. Our parents never treated B at home with blood products – he always received treatment in hospital.

10. B was unable to attend mainstream school due to the frequency that he required hospital treatment. I do recall tutors attending our family home, but I am not aware of why this was stopped. I presume Dr Winter (his doctor at the Queen Elizabeth Queen Mother Hospital in Margate) would have advised my parents to send B to Lord Mayor Treloar College, where he attended from the age of 11 as a full-time boarder. We are also sure that the local schools, especially at secondary age, would not enrol B as they would not accept the responsibility and that is why he was recommended to go to Treloars.

11. My sister and I believe that B contracted HIV and HCV through contaminated blood administered to him during the 1970s at Treloars, as we have since discovered how haemophiliac pupils here were treated as guinea pigs. No one ever consulted or informed B or our parents about any potential risks with the blood products being used. Indeed, as we all found out later, there was a huge cover-up about this by the government who were aware contaminated blood from America was still being used, but they chose not to divulge this. We are not aware of the doctors he was under the care of at Trealors.

12. We do not know exactly when B was diagnosed with HIV, but he had serious bouts of illness during the 1980s. B was a very private person – he never told anyone outside his small circle of friends that he had haemophilia as he wanted to live as normal a life as he could and did not want to be treated any differently by people. Likewise, we are not sure when he was told about HIV as he particularly would not have wanted to worry my parents, in particular our mother who was disabled and had her own ill health to deal with. We believe B was aware from the age of 18 that he had been infected with HIV. He

eventually told our parents when he became visibly unwell, but we cannot remember exact dates around this.

13. My sister and I would have found out about his infection in the mid 1980s and this would have coincided with when he started to become unwell.

14. We are not aware of any information provided about the infections to B or what tests were carried out on him. We are sure he would have been aware of the infection risk to other people, but he did not discuss this within our family.

Section 3. Other Infections.

15. Other than HCV, I am not aware that my brother contracted any other blood borne infections, aside from HIV and HCV as a result of receiving contaminated blood as treatment for his haemophilia.

Section 4. Consent

16. Our parents were never informed that the blood products B was receiving were contaminated and potentially life-threatening to him. No information was provided at all.

17. We can confirm that he was treated with contaminated blood without his and our parent's knowledge and consent.

18. It is believed now that Treloar pupils, including B were used as guinea pigs to test contaminated blood products. They were sitting targets for any government/health research.

Section 5. Impact.

19. The impact on B and the whole family, as a result of his infections with HIV and HCV was enormous. Living with severe haemophilia A had a profound impact on his life, but to have received infected blood on top of this was horrific.

20. B returned to the family home in GRO-B after completing his education at Treloars, but around the age of 20 he obtained a job as a sales representative at my place of work and came to stay on three occasions whilst living in GRO-B In-between, he either stayed at our parents or a couple of times rented with friends.

21. He had been taught to self-administer Factor VIII whilst at Treloars, but still went into hospital for very bad bleeds. I remember him receiving treatment both at St George's Hospital, Tooting and at Hammersmith.

22. I did notice he used to get tired often, but I did not realise there was anything wrong with him – he still suffered regular painful bleeds, so as a family we put everything down to part of the haemophilia.

23. He had bouts of serious illness and was very tired most of the time – which affected both his work and social life. He had to spend his lunch breaks sleeping as it was the only way he could get through the day and as his illness progressed, he had gaps of being unable to work at all.

24. B did become very ill over a period of time during the 1980s. Eventually, he told our parents and us what was wrong, but he also suffered with serious headaches that became worse over time. My mother had to coax it out of him what was wrong and he said that he had a brain tumour.

25. As B became more unwell, he stayed at my parents – eventually building a self-contained flat so he could retain some independence. I remained in South London at the time, but my sister lived just around the corner so would visit more often than I.

26. We were aware that B was taking medication but do not know the name of the medicine and what it was being taken for – however, he was far too ill and infected for anything to have a real effect. We cannot comment on the mental and physical effects of the medication.

27. We do not know what obstacles B faced in receiving treatment as he kept so much to himself, but more effective treatment only became available after his death.

28. In the 1970s and 1980s when HIV/AIDS was becoming known, it was prevalent and associated with the gay community and no link was ever made with contaminated blood products – as a result the stigma was huge and had a big impact on the infected. B never told anyone of his infection as it would have impacted his life enormously.

29. We were not allowed to tell anyone about B illness and the enormity of keeping everything a secret hung over us all.

30. B did not disclose anything to any of his employers or colleagues, so never experienced any discrimination and stigma in the workplace. He knew that he would not be able to hold down a job if he was open. We are sure that his last employer only became aware of his HIV infection after he died. They were very shocked but then realised why he had bouts of illness and seemed very tired all of the time.

31. B was unable to take out a life insurance policy because of his infections with HIV and HCV. He did a couple of holidays abroad after he was diagnosed, but we do not know if he took out travel insurance or disclosed his illness on any policy he may (or may not) have taken out.

32. I was nearly 12 and my sister 10 years old when B was born, so his haemophilia had a huge effect on our childhood. Our mother often said that we basically brought ourselves up from that age because she was hardly ever at home and always with B in hospital.

33. The impact on our mother was particularly hard – she spent all of B life being with him in and out of hospital due to his poor health, to then find out that he had been infected with HIV and HCV as a result of receiving treatment that was intended to help him was absolutely devastating.

34. Our father was of the generation where they did not openly discuss their feelings – obviously B infections with HIV and HCV affected him a lot but he never let this be known. The weight of this to contain internally must have been horrendous.

35. At the same time B was in hospital prior to his death, our maternal grandmother was in hospital with cancer. The day after B died, GRO-B went in to inform our grandmother and she passed away during the early hours of that night. She had not been expected to die so soon, but we believe the news of B led to this.

36. B was admitted to Basingstoke Hospital whilst visiting his girlfriend in Hampshire. He had travelled there for a weekend against our parent's advice as he was very very unwell. He was put on an isolation ward and on the occasions that I visited him I can honestly say that he was neglected by the medical professionals and left alone most of the time. Nurses never went into his room for more than what was necessary and consequently he became dehydrated and had to be put on a drip. Nurses never checked in on him all the time that I would visit and I put this down to the stigma and ignorance surrounding HIV at the time. Basingstoke Hospital were not equipped to care for him.

37. Tragically, B died at the age of 33 as a result of his infections with HIV and HCVs – he was so young.

38. Even after B passed away, we were told to tell people who asked, that he died of cancer. It was years later when the enormity of the contaminated blood scandal came to light, that we felt able to tell anyone the real reason for his illness and death.

39. The impact of B infection and ill health has passed on to our children and grandchildren. My eldest daughter is not a carrier and has two daughters but my youngest daughter is a carrier and had two babies aborted because they were haemophiliacs. She went on to have a son who does not have haemophilia.

40. My eldest daughter GRO-B was a passenger in a car accident at the age of 17 (in 1987). She fractured her neck and was very near death for 2 days but survived. She was operated on and then put in a halo traction and stabilised in bed in GRO-C for 4 months. Doctors had expected her to be paralysed from the neck down, but thankfully over that period she gradually regained most of her movement, apart from mobility problems and partial paralysis on her right side. Doctors warned us she could go into a depression which was apparently a common consequence of a traumatic accident. She did not at that time and after a year at home, gradually rebuilt her life albeit with some mobility problems. However, when B died and my grandmother 2 days later (on GRO-B birthday), it hit her very bad. She had been very close to both of them – it was a traumatic time as we had 2 funerals to deal with within a week of each other. This hit GRO-B very hard and soon after she went into a very deep depression based on her near-death experience, the accident, and the circumstances of B illness and death. Everything became too much for her to cope and she had counselling for a year. She still has depressive episodes and was diagnosed with ME 2 years ago.

41. GRO-B daughter has a son, GRO-B who has Haemophilia A, severe. When she was pregnant and informed of this, there was a huge impact on GRO-B and I. We could only remember back to B childhood and thought that it would be awful, but fortunately treatment has advanced so much in the intervening years. GRO-B is 11 now and has treatment every other day as a preventative measure, unlike B who had to wait until he had a bleed. He has gone into hospital on the odd occasion, but it is nothing like what B had to go through.

Section 6. Treatment/Care/Support

42. We do not know of any obstacles or difficulty that B may have faced in regard to him obtaining treatment care and support in consequence of him being infected with HIV and HCV as he kept everything to himself.

43. No counselling or psychological support was ever offered or given to B or to anyone in our family either before or after his death.

Section 7. Financial Assistance

44. B received a one of payment of £24,000 which we believe came from the Macfarlane Trust. This would have been around 1989/1990. We do not know how this was claimed and awarded, but presume the Haemophilia Society would have had some involvement.

45. He was given the payment on the condition that he did not seek any further award and he had to sign something to this effect in order to receive the money.

46. B used this money to have an extension built in 1991 on the side of our parent's house in GRO-B where GRO-B now lives. He wanted his own living accommodation, but with his illness he needed to be close to our parents for support – this was the ideal solution for them all.

47. Obviously, there should have been much more financial assistance offered, but B received no other help at all.

Section 8. Other Issues

48. Information around contaminated blood should have been given much earlier – they should have never waited until people became so ill that it was too late to save them. Contaminated blood should never have been used in the first place – especially after all the facts were known, yet the government continued to authorise its use.

49. Margaret Thatcher was the Prime Minister at the time and I distinctly remember our mother hated her after everything came out because the government had allowed this all to happen.

50. The contaminated blood scandal should have been dealt with years ago when B and our parents were still alive – he should have been properly

compensated but it is far too late for him now. Those still alive definitely need to be properly compensated because their lives have been wrongfully impacted.

51. We have no copies of B medical records and as far as we are aware, all documents were destroyed as part of the government cover-up of the contaminated blood scandal.

Statement of Truth

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

Signed GRO-B

Dated 4/11/2022