Witness Name:

GRO-B

|                                   | Statement No.: WITN7626001  |  |  |
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|                                   | Exhibits:   |  |  |
|                                   | Dated: 30 - 03 - 2023   |  |  |
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|                                   | INFECTED BLOOD INQUIRY  |  |  |
|                                   | WRITTEN STATEMENT OF GRO-B  |  |  |
|                                   |   |  |  |
| I prov                            | ride this statement in response to a request under Rule 9 of the Inquiry  |  |  |
| Rules 2006 dated 31 January 2023. |   |  |  |
|                                   |   |  |  |
| 1,                                | GRO-B will say as follows: -  |  |  |
| Section 1. Introduction           |   |  |  |
| 1.                                | My name is GRO-B My date of birth is GRO-B 1981 and my address is known to the Inquiry.   |  |  |
| 2.                                | I am married and we have a daughter who is four and a half years old. I   |  |  |
|                                   | grew up in GRO-B and I have a brother who is two years older than me.   |  |  |
|                                   |   |  |  |
| 3.                                | I intend to speak about my father, GRO-B: F , born on GRO-B   |  |  |
|                                   | 1950, and his infection with Human Immunodeficiency Virus (HIV). In   |  |  |
|                                   | particular, the nature of his illness, how it affected him, the treatment he received and its impact on him, our family and our lives together. |  |  |
|                                   | received and its impact on min, our family and our lives together.  |  |  |
|                                   |   |  |  |

- 4. I was a child when my father first became ill. Therefore, I do not have much information about the medical aspects, and all I know is secondhand information from the adults around me growing up.
- I confirm that I am not legally represented and that I am happy for the Inquiry Team to assist with my statement. I wish to provide my account anonymously for personal reasons.
- The Inquiry Investigator has explained the Inquiry's statement of approach and 'Right to Reply' procedure. I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.

#### Section 2. How Affected

- My dad was diagnosed with severe haemophilia A when he was a child, and before his diagnosis, there was no history of haemophilia or an identified carrier in the family.
- 8. My parents did not keep this diagnosis a secret, and from a very young age, I was aware that my dad was a haemophiliac. I think I was around five when I became aware, but I could have been younger.
- According to my mum, there is no way to narrow down when my father became infected with HIV beyond the late 1970s or early 1980s.
- 10. Growing up, I knew my dad was unwell because he sometimes required a stick to walk, especially when he had a bleed. Gradually, he required the stick a lot more, especially towards the end of the 1980s.
- 11. I don't recall specifically any blood products my dad received besides Factor VIII. I knew there was stuff in the fridge, but I did not know what it was.

| 12. | My dad worked as a full-time civil servant for the council GRO-B I remember this as his office was opposite GRO-B at the time.   |
|-----|--|
| 13. | My dad was a passionate football fan and enjoyed attending football matches at Tottenham Hotspur stadium. Growing up, my brother and I were too young to attend at first, so it was just my parents, and they would usually drop my brother and me at our grandparent's house. |
| 14. | My dad was under the care of St Thomas' Hospital and usually made day trips to the hospital whenever necessary.  |
| 15. | The local hospital near our house GRO-B was St Peter's Hospital in Chertsey, but I don't know that my dad ever attended there. As far as I can remember, my dad went to St Thomas's Hospital for everything related to his haemophilia.  |
| 16. | My mum believes it was after I was born, sometime around 1983 or 1984, when my dad was diagnosed with HIV. I think that the diagnosis came after we had moved to the house I grew up in GRO-B However, my brother and I did not find out about this diagnosis until 1991.      |
| 17. | I am sure the diagnosis came as a shock to both of my parents. I don't know if my mum was with him or if she found out after the fact.   |
| 18. | Although my brother and I were unaware of the diagnosis, I remember that the television camera crew came around to our house to film my dad, which turned out to be for the GRO-B on AIDS in 1985.   |
| 19. | I don't know how the documentary came about, but my dad was a passionate person. He was a part of the trade union at work and may  |

have been a part of the haemophilia society. However, my brother and I

did not grow up knowing other children or families of people with haemophilia. My mum was not in the programme.

- 20. I don't think we had a copy of the tapes in the house, but I know I had seen it because I still remember watching my dad on the television while he sat in the brown chairs in our house talking to camera. I never saw the programme again for years until my husband tracked it down and bought a copy for me as a birthday present.
- 21. I have never been under the impression that there was any pushback or negative consequences due to my dad appearing in the documentary. My mum and I do not really talk about my dad and never have done over the years, so it is difficult to know some of the details of things that happened at the time.
- 22. In May 1991, when I was nine and my brother was about 11, my dad informed my brother and I of his HIV diagnosis. We were in our living room at the time, and I think we were told not to tell anyone.
- 23. My Dad stopped doing things like coaching the local cubs football team at my school and was getting weaker and looking thinner. It was perhaps after Christmas in 1991, he stopped working and seemed much more bed bound. Towards the end, he went to the GRO-B Hospice. My dad died or GRO-B 992.
- 24. My mum and brother visited my dad at the Hospice after he died, but I did not. My dad attended a Church of England church GRO-B and his funeral was held there.
- 25. The funeral was packed and as far as I am aware, there were no restrictions on whether it should be a funeral or a cremation. However, I know that his death certificate lists the cause of death as pneumonia, but I am not sure how this came about.
- 26. We were still at school at the time, and my mum told me that if anyone asked, I should say that he died of pneumonia.

27. I have never been informed that at any stage before my dad's HIV was diagnosed that my parents were warned about any risks associated with Factor VIII. Certainly, my mum has not given me that view, and from conversations with her, I don't think she did receive any warnings regarding the blood products being contaminated.

### Section 3. Other Infections

28. I do not believe that my dad received any infection other than HIV due to being given infected blood products.

#### Section 4. Consent

29. I am not aware of any issues regarding consent or if my dad ever underwent treatment for the purposes of research.

## Section 5. Impact

- 30. Although my dad grew up with severe haemophilia, I do not think it affected his education or career prospects when he was growing up. He grew up in GRO-B and attended a regular school. By the time I was born, my dad worked in local government and was perhaps the head of his department, which had something to do with pensions. I believe he was happy in his job.
- 31. When I was between the ages of five and nine, I was only aware that my dad had haemophilia, which affected his mobility. He did not walk very long distances or run, but he still went out and did things. We went on holiday as a family, but we did not do more active things.
- 32. He managed the local Cub scouts football team and coached the young boys, some of whom were my friends and in my school year. He was still working and coaching the boys until a year before he died. He

used to attend church, and in many respects, life carried on even after his HIV diagnosis.

- 33. When my brother and I were informed of my dad's diagnosis, I can't recall if we were told it was HIV or AIDS, but they said it meant my dad would die prematurely. I remember being frightened as well, and there was an indication that we should not mention it to anyone, but they did not go into too much detail. It was only after my dad died that my mum explained how there could be a stigma attached to HIV.
- 34. I do not know if the diagnosis had an emotional impact on my dad, and I am not sure I was of an age where I would have been able to recognise it. In those days, people did not talk about such things with children.
- 35. I do not think we faced any stigma after my dad took part in the GRO-B

  GRO-B in 1985. We have a relatively small family who lived around the same area, and we still went around to some of my mum's friend's houses, and we had friends at school, so we had a decent social life.
- 36. My mum mentioned that one of our neighbours saw my dad on the television, so she was aware that people had seen the program, but if there were any negative repercussions, she did not mention this. As mentioned above, my mum and I do not discuss my dad or his HIV diagnosis. From her perspective, it is something that happened a long time ago.
- 37. I think my parents would have been worried about the future after my dad's diagnosis with HIV. It was the 1980s and there was a lot of stigma in the media at the time.
- 38. My dad loved football and as a family, we supported Tottenham Football club. My parents used to go to games when it was just them,

and when my brother and I were old enough, we would go along too. It was what we did as a family every other weekend and was a significant aspect of my formative years.

- 39. My parents had a dedicated friend whom they sat with, and to date, the same friend still sits with my mother and brother whenever they go and watch the game. I still go to watch the games, but I sit elsewhere in a cheaper seat.
- 40. My dad had even travelled to eastern Europe in the 1970s to watch Tottenham play Belgrade, I think this was in GRO-B After becoming sicker, he had to stop attending football matches, which I am sure would have been devastating for him.
- 41. I remember the year he stopped coaching the cub-scout team was after they had just won a trophy, and all the boys at school were asking why he could no longer coach them, but I could not reveal the real reason for this.
- 42. My dad's death affected the family dynamic considerably.
- 43. The first few years after my dad died were quite a bleak time. My mum had no one else to help her on a daily basis.
- 44. Now that I am a parent, I understand the importance of having a second adult to check in with.
- 45. As a teenager, I did not have anyone else to talk about these things with, and I did not feel like I had a sibling in the way others did. It was quite isolating at the time because everyone else had two parents and what seemed like a "normal" family. Again, it is only looking back that I realise how many of the usual family things I missed out on back then. My husband will sometimes reference an activity he did growing up with his family and I realise that it is not something I have done. My

mum and I later got up to doing things just the two of us, but we would never speak about my dad at all.

- 46. Not only did I lose my dad at an early age, but I was also deprived of the opportunity to have a relationship with him now that I am an adult, and get to know him as a person in the way most people do. He has missed out on momentous occasions and milestones, such as watching me turn 18 and telling me off for drinking. He could not be at my wedding and never got to meet his grandchild.
- 47. I started playing football after he died, so he did not live to see me play football, and he did not know who I became as a person and only ever knew me as a child.
- 48. A few days after my dad passed away, my mother and I went to Legoland in Denmark for a long weekend. We had pre-booked this trip, and we went without my brother. I remember my mum telling me beforehand not to worry if she broke down or seemed like she was not coping because that's what happens sometimes when people lose someone they loved.
- 49. Although she warned me about having a breakdown, I never saw her breakdown that weekend. The only time I saw her really upset was when she lost her dad, my grandad, three years after my dad died. My grandad was also cremated at the crematorium GRO-B where my dad had been cremated just three years before.
- 50. My mum was only 38 years old when my dad died. She mentioned that it was difficult for her because it was around that age that people go out in couples because their children are now teenagers and old enough to be left behind at home, and my mum didn't have anyone to go out and socialise with. So, I think she was probably lonely for a while.
- 51. My mum has a new partner, and they met seven years later and have been together since. My mum is quite strong and pragmatic. I don't

- know if she does not talk about my dad because it would be upsetting or because she doesn't want to dwell on it.
- 52. Looking back now, that conversation with my mum in Denmark had an impact on me. I thought I had to be strong for my mum, and that, coupled with the fact that I could not talk about my dad's death with my friends at school, affected my emotional well-being in the long run.
- 53. It had a massive impact that I did not realise until I was older. As a child, you believe that your parents will always be there for you, but losing my dad at an early age taught me that this was not always the case.
- 54. In my early 20s and 30s, I experienced bouts of depressive episodes and coming to terms with the loss of my dad was a contributory causal factor. I believe there was a sense that because something terrible happened to my family when I was so young, a fear of terrible things happening resides within me.
- 55. I have since been diagnosed with cancer and fought it three times, and not having a second parent when going through something as life changing as cancer makes it that much harder. Also, knowing that my dad died at a young age means each time I have lived with the awareness that young people can die too. Essentially, knowing that my father died at such an early age has had an effect on my own well-being and sense of mortality.
- 56. I had a test at the age of 11 or 12, which checked my clotting factor, and confirmed that I am a carrier of the haemophilia gene. When my husband and I were trying to have our baby, we had to undergo genetic counselling because I had been diagnosed with cancer, but also because of haemophilia.
- 57. As a result, we tried to obtain records of my dad's medical files from St Thomas Hospital, but the hospital said that they do not hold any

records for my dad. I do not know if it is normal because he died in 1992.

- 58. My dad worked in local government, which meant he had a good pension. After he died, my mum continued to receive my dad's pension, which was financially sufficient for us until my brother and I completed our education.
- 59. My parent's mortgage was eventually paid off. I do not know if my mum had anything to do with pneumonia being listed as the cause of death on my dad's death certificate, but I imagine that that kind of information regarding an HIV diagnosis could have had a negative impact on being able to make the life insurance claim.

#### Section 6. Treatment/Care/Support

- 60. I do not know if my dad felt like he was getting the best treatment available at the time. He was critical of the government but not any specific medical professional.
- 61. As far as treatment goes, I know my dad was on some medication, but I don't know if the treatments for HIV were already available at the time. I believe he had a specialist nurse, although I cannot recall her name, and I don't know if she was a good or bad nurse.
- 62. I do not think there was any offer of counselling or psychological support before my dad was informed of his diagnosis or afterwards for him or any of us in the family. I don't know if my mum would have accepted the offer for me if it had been available.
- 63. I did not even know that bereavement counselling was a service offered to people until I was in my 20s and a friend I had grown up with lost a parent and mentioned that they had been offered counselling support.

## Section 7. Financial Assistance

- 64. My mum has received some financial support from the Macfarlane Trust, but I do not know any details around this.
- 65. My mum has only recently begun to receive monthly support from the English Infected Blood Support Scheme (EIBSS) within the last 18 months. In October 2022, she received the £100,000 interim compensation from the EIBSS.

## Section 8. Other Issues

66. I have always been of the view that the government knew that the blood was contaminated or was at risk of being contaminated. I don't know what has informed this view, but it is one I have held long before this Inquiry.

# Statement of Truth

| I believe that the | facts stated in this witness statement are true. |
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| Signed             | GRO-B  |
| Dated              | 30 March 2023                                    |