Witness Name: GRO-B

Statement No. WITN7625001

Exhibits: Nil

Dated: 25 / 4 / 2023

INFECTED BLOOD INQUIRY

WRITTEN WITNESS STATEMENT

OF

GRO-B

I provide this statement in response to a request under Rule 9 of The Inquiry Rules, 2006 dated 24th January, 2023.

I, GRO-B will say as follows:-

Section One - Introduction

1. My full name is GRO-B and I was born on GRO-B 1961 in Kent, my parents having been GRO-B and GRO-B GRO-B, both of whom are now deceased. My father had been an accounts manager and my mother a nurse until they had children, when she became a housewife and for many years a full-time mother.

2. I was one of five children, having three brothers and a sister of whom I was the eldest girl. Unfortunately, two of my brothers were found to have Haemophilia, but neither my sister, myself or my other brother have, or had, this condition.

3. I understand that Haemophilia is an hereditary ailment, but in so far as my parents were concerned, both were, and had always been, fit and healthy people. However, my mother was a carrier of haemophilia meaning that statistically, half of any sons she had could inherit the condition and that half of any daughters may be carriers. Her being a carrier was only picked up after we had all been tested, as a family, following my brother GROB: B1 having become so unwell (as I will shortly explain). At the times of her having fallen pregnant, she had not known that she was a carrier, and there had been no familial history which may have alerted her to this fact – no one knew.

4. Both boys were classified as having mild haemophilia, and received treatment by the National Health Service (NHS). Unfortunately, one B1 contracted the Human Immunodeficiency Virus (or 'HIV' as it is more commonly known), and died as a direct result, the HIV having developed into the Acquired Immune Deficiency Syndrome (or 'AIDS') ; whilst the other GROB: B2 contracted Hepatitis C (also known as HcV and / or Hep' C), but remains alive.

5. Using this witness statement, I intend to tell the Infected Blood Inquiry of my family and the nature of the illness(es) which my brothers had, how they were affected by ill health, its impact upon us all, and the treatment they received such as may be known to me.

6. Two of my brothers, B2 and GRO-B have also provided the Infected Blood Inquiry with written witness statements. My sister has not as yet provided a statement, but I believe my parents would have done, had they been able to do so, but sadly my father passed away in 2016 and my mother in 1997, just five years after we lost B1 (in 1991).

Section Two - How Infected

7. My immediate family tree (GRO-B) is as detailed below:-

FATHER -------------------- MOTHER

GRO-B

CHILDREN

GRO-B | **B2** | **B1** | **GRO-B**

8. As a family, we had moved home four times, on one occasion following our dad's work, although he only actually worked in two different locations and on one of those moves only I had been born. As a consequence, I was born in Kent, my brothers **B2** and **B1** were born in Surrey, whilst **GRO-B** and **GRO-B** were born in Surrey although we had all been living in Hampshire at that time, as a family, when the matters with which we are concerned commenced.

9. **B2** and **B1** were first diagnosed as having Haemophilia at some time between 1970 – 1971, when **B1** was aged about seven and **B2** eight years of age. Until then, there had been no indication that there may have been anything untoward with their health, they were just little boys growing up.

10. For clinical reasons, it had been deemed necessary for **B1** to have his tonsils removed, a procedure which was conducted at a hospital in Reading. It should have been a simple procedure, a tonsillectomy being a minor operation which many thousands of children undergo each year, but following the operation, **B1** bled a lot and the clinicians seemed wholly unable to do anything about it.

11. As a result, whereas he should have been a patient who passed in-and-out of hospital very quickly, he spent a month or thereabouts as a hospital inpatient, having to be taken in-and-out of theatre, as doctors sought to staunch the flow of blood. He was so poorly at times that he was held in intensive care, and I can remember visiting and seeing him with plugs in his nostrils, as he was bleeding nasally as well. He would be taken into theatre, they would remove the plugs, he would come out, and the bleeding would start again no matter what they may have done in an effort to stop it.

12. Eventually, after about a month, the clinicians appeared to admit defeat, and without a definitive diagnosis as to what may have been wrong, transferred his care to The John Radcliffe Hospital in Oxford, for specialist consideration as it was feared that he may die if the bleeding could not be controlled.

13. At the time, this must have been really worrying for B1 and for our parents, but I was just nine years old, and didn't really think too much about it – one of my brothers was ill, but he was in hospital so he'd get better, or be made better, given time, it was no big deal. However, now looking back, to some extent I think that our parents actively shielded my siblings and I from what may have been happening, especially as no one actually knew what was going on.

14. It must have been a particularly anxious time for my parents, and in particular my mother whom I can recall having wanted B1 to be allowed to come home, as she did not want to watch him die in hospital – if he was going to die, then she wanted it to be at home, surrounded by his loved ones and in familiar, less frightening, surroundings.

15. I remember her having received a telephone call from the hospital in Reading, and having said as much to whoever she had been talking to, when they suggested transferring him to the John Radcliffe. She really didn't think he was well enough to be moved anywhere other than home, after all he had been in hospital for a month and the doctors hadn't been able to find out what was happening, so why would another hospital have been any different?

16. However, our father was at the time working in London, and went to see a specialist (I do not know in what particular field), in Harley Street. As a result of what he was told or learned, he was able to persuade our mother to allow B1's transfer, as the specialist had convinced dad that it would be for the best, and as such mum backed down and B1 was transferred.

17. Once at the John Radcliffe Hospital, tests conducted (I believe these to have been blood tests) revealed that B1 had Mild Haemophilia which had been the reason for his continual bleeding - he lacked an element within his blood that would have allowed his blood to clot, and in its absence he bled out.

18. As a result of his test result, my siblings and I all had to be tested for haemophilia, and this is how they found out about B1 –the rest of us were clear, none of us either having haemophilia or being carriers of the same, but B2 also had it.

19. Taking into account the lack of any familial history of haemophilia or of any similar ailment, and the fact that each boy had reached seven or eight before there had been any indication of haemophilia, their diagnoses came as a complete shock, and whereas it was reassuring for the rest of us to have learned that we did not have this complaint, it was quite worrying for B1, B2 and our parents who would now have to care for them, and reconsider how they went about things.

20. None of us were particularly well informed at that time, especially as I was only nine years old when tested, and for those of us that didn't have this problem, nothing really changed, but it was a real worry for our parents.

21. Having discovered what the problem was with B1's clotting, he was treated in the John Radcliffe Hospital using what I believe to have been the blood product Factor VIII, and discharged fairly quickly thereafter. Life carried on, things returned to normal at home, and we all just adjusted and adapted to the new situation, as children tend to do.

22. B1 and B2's care was referred back to the hospital in Reading which was about an hour from our home. They were able to provide Factor VIII to B1 or B2 should it be required, but they were generally fine, as being only mild haemophiliacs, they did not have, and I do not believe were then offered, prophylactic therapy, so initially they only ever had Factor VIII on demand, i.e. at hospital, following any incident (bleed) requiring it.

23. As we were living in Hampshire at that time, I have been asked if either of them were sent to the Lord Mayor Treloar School / College, as pupils with haemophilia, but they were not and nor were they treated through a dedicated Haemophilia Centre located at that site.

24. Fortunately, our mother was able to call upon her nursing experience to care for B1 and B2 and although they had to be cautious as to what they did and how, such as with the type of sports they played, their condition did not appear to adversely impact upon their lives.

25. Our parents took the view that it would have been unhealthy for them to have been over-protective, the 'wrapping them up in cotton wool' sort of thing, so they let them go about things as their peer groups did, playing football and so on, and if either took a bad knock, then they'd be taken to hospital for some Factor VIII, but only if the bleed didn't subside of its own accord or was clearly severe in nature. Mum, having been a nurse, was able to monitor this.

26. I am unaware of either B1 or B2 having been given whole blood, or Cryoprecipitate, as a means of treating their haemophilia, and am only aware of Factor VIII having been used, but it is entirely possible that either of these treatments, or both, were used, but I am unaware of it having happened.

27. I only know of Factor VIII, but I do not know when it became available. As such I have attributed all of their treatment to Factor VIII, but it is possible that something else may have been used, I just do not know this for a fact.

28. I believe that both were treated at the hospital in either Reading or Oxford until 1972 when we moved as a family to GRO-B and their care was transferred to a hospital able to administer Factor VIII there. The hospital in Reading was closer to home, so it may well have been there rather than Oxford, but on reflection and with the passage of time, I am now unsure. As with these hospitals, once care was transferred, I am not sure which hospital became responsible for their treatment, as there were more than one in each location, some of which have since closed.

29. As before, any treatment they required was administered in hospital and 'on demand' following a bleed. At that time, we held nothing at home for prophylactic use, and in so far as B1 is concerned, I do not think that we ever did.

30. I never really knew too much of the haemophilia myself, as I grew up, I just grew alongside it. Two of my brothers had it, but apart from understanding that it was a genetic condition, and that if they either took a knock or were going to have a tooth out or something like that, it was of no real consequence to me – in our home it was 'normal,' so I never really considered it too much and our parents kept us at arms-length regarding anything that may have been going on, beyond that which we needed to know as children, to protect us.

31. B2 and B1 just put up with things, and appeared to cope really well. They each seemed to know their limitations, not that they necessarily observed them, and as a family we carried on as normal, although if either of them required dentistry, they had to go into hospital for it, which was unusual.

32. For B2 in so far as I am aware, his treatment regime remained the same, treatment on demand, but in so far as B1 was concerned, this changed as he progressed into adulthood.

33. B1 left home to attend University, and then moved out to live in Wales where he had found work as an instructor with a company called GRO-B, who provided outdoor adventure activities for children and young people, school groups and the like, something they still do. He wasn't permanently resident in Wales, but lived there for work purposes as and when necessary.

34. This was a position which rather flew-in-the-face of lifestyle management for a haemophilia patient, and exposed B1 to the risk of various knocks and bumps, and as a consequence, bleeds. To be able to take the job and above all to cope with the everyday risks posed by the nature of his work, his treatment changed from being given Factor VIII on demand following an incident to one of taking Factor VIII in advance, to offset any problems he may face. He received a stock of Factor VIII, and self-administered it.

35. He was now in his early twenties, appeared to thoroughly enjoy the nature of his work, and through the use of Factor VIII was able to do something which may not have otherwise been possible for someone with haemophilia, albeit only mild haemophilia.

36. I never really spoke to B1 too much about this, what he had to do, what it meant for him, and so on, but I know that it was a major worry for our parents who knew the risks he was facing and could only hope that prophylactic Factor VIII use would prove effective – he was out of sight, but never out of mind from their perspective.

37. I know that B1 went from reactive use of Factor VIII to proactive use, as described and for the reasons detailed, but I do not know if this was a deliberate change in treatment plan *or* as part of a trial, but as his job was very physical and he needed to keep his Factor VIII levels 'up,' his plan changed.

38. B1 was single and living away from home, and by this time B2 had also moved out, was married, had a young child, and was living with his family on the outskirts of GRO-B By 1985, I had also moved out, married and had two children of my own, one a mere babe in arms at the time.

39. Completely out of the blue, I received a 'phone call from B1 He didn't say much, as the call was very brief in nature, just that, *"I am in a hospital in Wales ... I have HIV... I thought it was AIDS … I have tried to kill myself ... I have no money on me ..."* and then the call ceased.

40. This was in the time before the mass use or availability of mobile 'phones, and B1 had called me at home from what appeared to have been a payphone. I had no idea where he may have been at the time, and so I immediately began working my way through the various hospitals in Wales, calling one after the other, in an effort to locate him.

41. Although I cannot now remember the hospital name, eventually I located him and was able to speak to him at the hospital, by 'phone. At the time, I knew our parents were away from home, on holiday with GRO-B and GRO-B so as he had nowhere else to go, in light of what he had apparently done to himself, I told him to come to me.

42. Apparently, knowing that he was going to be discharged from hospital, and wanting to come 'home' he had called me. In so far as I am aware, as soon as

the hospital had treated his physical injuries, he was discharged and came straight to me – the doctors had done nothing to address the mental distress which had led to his suicide attempt.

43. I do not now recall whether B1 told me how, when, where, or how he had been told that he had contracted HIV, be that in the 'phone call or once he had arrived, but he told me. Apparently, he had been having regular blood tests as a result of his Factor VIII use – to check its efficacy and the necessary levels I his blood, and one of these tests had revealed HIV.

44. B1 confided in me that having learned that he had HIV, and being scared following substantial media coverage of both HIV and AIDS, he had taken the decision to end his own life so as not to become a burden to anyone. He told me that he had gone to a mountainside where, alone, he had slit his wrists thinking that as he had haemophilia, he would bleed out and die.

45. However, having apparently passed out, he said that he had then woken up, and having failed to take his own life as he had intended, drove himself to hospital seeking help.

46. Here my recollection of events and those of my brother GRO-B are unclear, but he believes that he had been told by B1 that he had been found by a passer-by and taken to hospital. Whatever the case, and it is entirely possible that he told us different stories, he ended up in hospital where they patched up his cuts, most probably gave him some Factor VIII, and then released him without having sought to investigate *why* he had acted as he had, and deal with it.

47. Given time, his wrists healed, but the mental anguish which had led to this sad event, never did, although to a certain extent he learned to live with HIV.

48. As a child, I had been well-aware of haemophilia, and its impact upon my brothers, but apart from whatever I may have been told at any given time, didn't really pay much attention to it I just got on with things and let my brothers deal with it alongside my parents. It was a health condition which the family lived with, and managed. In contrast, in 1985 HIV/AIDS was being mentioned

everywhere, and you could not help seeing or hearing information about it; through frequent television, radio and newspaper items to posters and hoardings.

49. I became aware of HIV/AIDS as a result, and by then having become interested, sought to understand more than I ever had about haemophilia together with HIV/AIDS, as the latter appeared to be impacting upon so many people. In particular, I watched an episode of Panorama, a mainstream television current affairs programme which focussed upon the large number of male homosexuals being inexplicably stricken with an unidentified illness, asking the question as to *why?*

50. There was also a lot of scaremongering going on, worrying health promotions encouraging you to practise 'safe sex,' and politicians of all sides being quite vocal on the issue. As a result of all of the hype, and as I was only 23 years old, but married and with two young children, it became a major concern for me – how did I keep my husband, children and myself safe? What, if any, risk did B1 pose? How did I keep us free of HIV?

51. When B1 arrived at our home following his discharge from the hospital in Wales, my husband (now my ex-husband) had provided him with some clothes to wear, and he had taken dinner with us – what was I to do with the cutlery he had used, the crockery?

52. I found that I was asking questions of myself that I could never have envisaged doing before. HIV had made me wary of my own brother, at a time when he was at his lowest possible ebb but it was very difficult for us yet he really needed our help and support. He was just twenty-one years old and had received the most impactive, life changing news, information which had led to him attempting suicide. He was my brother, I couldn't just abandon him pro push him aside.

53. B1 would come to us for a meal, and his condition became a major worry each time. Could he kiss our children, give them a cuddle, just how contagious was he? The public atmosphere of the time was quite toxic, so you didn't speak

to anyone for fear of B1 s HIV status being revealed, and B1, or us, or both being targeted as a result.

54. On the evening of his arrival from Wales, my husband and I had been due to host a meal for some neighbours, but although we had wanted to, we couldn't reschedule, so we made up a story about B1 to cover his wrists having been in bandages, telling our neighbours lies which had been a knee-jerk reaction borne out of a fear of exposure. There was a clear elephant in the room, but no one would speak of it.

55. Following B1 having come to us, having the meal with our neighbours, and being given some clothes, whereas we wanted him to stay, he went to our parent's home, although we knew that there would be no one there.

56. At some point in time he told B2 of his HIV diagnosis and what he had done as a result. I do not know when this happened, once he had left us, or once he had arrived at our parent's home, but it was the same day. He had apparently told me first, which I found unusual, as with them both having haemophilia and accordingly having been very close to one another, I would have thought he'd have contacted B2 first, but he didn't. One thing he told us both was that *we were not* to tell our parents.

57. I do not know if B1's diagnosis prompted B2 to take an HIV test, or even if he had one, but if he did he kept it to himself, which is his way. I very much believe that he would have done, and that he would have done so very soon after being told. I have no reason to believe that B2 had been infected with HIV B2 had a small child at the time, so I am pretty sure that he would have undergone testing, as it would have been sheer folly for him not to have done so.

58. In 1985, with little being known about HIV/AIDS, a diagnosis of having HIV was regarded as being something of a death sentence to those who had been infected. It also carried a dreadful stigma, in no small part a result of the media frenzy and what we now know to have been misinformation, especially as to any modes of transmission, which focussed on personal lifestyle choices. This

led to a lot of discrimination and as a result, B1 didn't want to talk about it, with anyone, not family, not friends, no one at all.

59. The fact that he had HIV led directly to B1 leaving his job with GRO-B – to work there had been hard enough with haemophilia, but he could deal with that and he wasn't likely to pass haemophilia on to anyone else, but the same could not be said of HIV, so he quit as he couldn't mitigate the risk he posed to others. He left GRO-B and sought an alternative, 'safer' form of employment.

60. B1 joined the I.T. multinational GRO-B, and travelled around a lot with his work, living in different places, including London, but it was fairly risk free in so much as he was unlikely to pose a risk of infection to any others due to the nature of his job, but he didn't tell GRO-B that he had HIV when he joined – he told no one, he kept it all to himself.

61. I do not know if B1 ever received treatment for HIV, but I very much doubt it as the forms of treatment we now see being used to control HIV, allowing those infected to lead fairly normal, fulfilling lives, simply didn't exist back then.

62. I do not know if B1 continued to self-administer Factor VIII following his move from GRO-B to GRO-B but there would have been less need for him to have done so in his new role as it posed far less risk.

63. When they returned home, I spoke to my parents about B1 and asked if they had heard anything, but without letting on that I already knew. Clearly, they had been told, but mum wouldn't or couldn't talk about it, merely telling me that she had spoken to B1 and he'd told her about *"it."*

64. It became very difficult for the family, with or without B1 being present, as although we all knew that he had HIV, none of us would talk to one another about it, my parents wouldn't, my brothers and sisters wouldn't, so we suffered in silence, both as individuals and as a family, none of us feeling able to bring the subject up with anyone else.

65. B1 was no different, he wouldn't discuss HIV with us as he didn't want to talk about it either, and he only ever told those who absolutely needed to know –

such as a doctor or dentist who may have been treating him, but no one else. He went from someone who as a person with haemophilia actively courted risks whilst working for GRO-B, to someone who avoided all risks having joined GRO-B GRO-B, and he kept himself to himself.

Section Three - Other Infections

66. I am unaware of either B1 or B2 having contracted any other viruses / diseases to those I have mentioned, as a result of having been given contaminated blood and / or contaminated blood products.

67. B1, having been given contaminated blood / contaminated blood products contracted HIV. B2, having been given contaminated blood / contaminated blood products contracted HcV – neither of my brothers had exposed themselves to any of the known or suspected 'risk factors' associated with HIV and / or HcV infection, which left contaminated NHS blood and / or contaminated NHS blood products as the only source of the viral infections they were found to have.

68. I say this, as following his death, or in the period leading to it once he had been diagnosed as having developed AIDS, either B1 or B2 told me that the source of his HIV infection had been traced back to a contaminated batch of blood product he had been given as a haemophilia patient, which is another reason for my belief that it was the use of Factor VIII as opposed to whole blood, which had led to him having been infected.

69. I believe that a similar 'look back' exercise may have also identified the source of B2's Hepatitis C infection, but I am not as sure of this as I am with B1.

Section Four - Consent.

70. I am unable to assist the Inquiry as regards issues of consent – at the relevant time, this would have been addressed by my parents, and once they reached adulthood, this issue would have passed to either B1 and / or B2 to address, as and when necessary.

Section Five - Impact

71. B1 enjoyed his work for GRO-B and met a lady there GRO-B whom he went on to marry. He was open with her as to his health situation, but this proved to be no deterrent to their relationship, as perhaps it may have been for others. They were very much in love and that was all that mattered to them.

72. B1 was able to work for a while, his HIV having been no impediment following his initial HIV diagnosis, and he remained well for a couple of years, but then various things began to go wrong with his health. Odd little things, a variety of divers ailments and conditions came his way, and he appeared wholly unable to avoid anything that may have been circulating within the community at any given time.

73. His doctors tried to get to the bottom of this, but as I have already said, little or nothing was then known of HIV, and they were unable to come up with any particular diagnoses, or treatments, even suggesting at one time that he had Addison's Disease, another condition impacting upon the immune system – but it was not Addison's Disease, it was HIV which had severely impaired his immune system.

74. Shortly after the birth of my third child in 1988, B1 began to feel particularly unwell and in 1989 he had to be admitted to hospital in GRO-B close to where he was then living, where he was found to have developed pneumonia.

75. I went to visit him, and whilst doing so he told me that the clinicians had diagnosed AIDS. B1 explained to me that HIV had progressed to AIDS and that his having pneumonia had effectively been a signpost for the same. To me, he appeared visibly unwell, and had clearly lost a lot of weight. It was not what I wanted to hear or see and was very upsetting.

76. He had continued working until developing pneumonia, and in an effort to cover up the reality of his situation, B1 had told his employer and colleagues that he had cancer.

77. I wanted to look at his treatment options, desperate to find something positive for him and to learn more myself, but found that the only form of treatment was the use of Azidothymidine (known as 'AZT'), an anti-retroviral medication.

78. I learned that this did nothing to clear the patient of HIV/AIDS, merely slowed its progress in some manner or form, and my research, together with what B1's doctors had told him, made it clear that AZT patients rarely lived longer than two years once they commenced treatment. It was therefore clear to B1 his wife, and my family and I, that unless a more effective form of treatment was found, he didn't have much longer to live.

79. This news came as a dreadful shock to us all – we knew that he had HIV; we knew that HIV could develop into AIDS; and we knew that AIDS could, and most probably would, kill you if you were infected; but all the same this news and the stark reality of what he then faced, came as an extremely heavy blow to us all.

80. The fact that B1's life was limited came as a particularly hard blow to his wife, even though she had married him knowing that he had HIV. She had always been very caring and supportive of B1 and this continued, at least when they were together, but she was also suffering emotionally – she just did her best not to show this to him as, to varying degrees of success, we all did.

81. B1 worried whether or not his wife would be financially secure, as and when he passed away, and was concerned for the position he may leave her in. This anxiety was something which steadily grew within him, more and more as he struggled on.

82. B1 and his wife sought to make the most of the time they had left together, and when he was well enough tried to fill their days with a variety of activities, but their lifestyle altered significantly as his health continued to deteriorate.

83. At twenty-seven years of age, and in failing health, B1 made it quite plain that although unwell he did not want to die at just twenty-seven, and appeared determined at the very least to make it to twenty-eight, so in spite of his having by then become quite unwell, he hung on, and reached 28, but passed away only five days or so later.

84. By the time of his death, B1 had told us that he no longer wanted to receive any treatment, it wasn't apparently doing him any good. It was almost as if he had set himself the target of his 28th Birthday, and that once he achieved that, he knew he couldn't go on any longer and allowed nature, and the virus, to take its course. He had by then, and in his own words, *"had enough."*

85. When B1 became very ill, I spent a lot of my time researching HIV and AIDS, consumed as I was, by a need to know more about them, understand what was going on, and above all how they may be treated. Back then, it was far more difficult to conduct research, there was no 'google search' internet facility readily available at your fingertips, or anything similar to rely upon, so everything took much longer.

86. My husband complained about my conduct, what I was doing, why, and to what end? He told me that I had become obsessed with it, and I now think that if this conduct didn't cost me my marriage then it was a least a major contributor to our marriage having collapsed.

87. B2 a fellow haemophilia patient who like his brother had also become infected, albeit with Hepatitis C as opposed to HIV, had been a significant source of support for B1 especially towards the end of B1 s life as he became a regular visitor, helping out with all sorts of things, including B1 's feeding.

88. As someone who had used the same products as B1 as a haemophilia patient, and who had also become infected, the situation hit home very hard for B2 who seemed to think that, *'there but for the grace of God go I,'* as he believed that he could just as easily have contracted HIV and found himself in a similar position to B1 B2 was concerned for his future, as he still had to use Factor VIII, and would continue to have to do so as a person with haemophilia – there was then no alternative to Factor VIII use following a bleed.

89. B2 worried that he too had been handed some form of death sentence by the NHS, and each time it became necessary, had to weigh up the pro's-and-con's

of taking Factor VIII knowing what had happened to his brother. Did he act to save his joints or instead suffer ta bleed and its consequences, to save his life?

90. I do not know exactly when B2 found out that he had Hep' C, as he had kept the news to himself, and continued to do so for a very long time. By the time I myself found out B1 had passed on.

91. Whatever the timing of his diagnosis may have been, I believe that B2 was still married at the time he learned that he had Hepatitis C (he later separated), but by the time I found out that he had had it, he had been treated and declared 'clear.'

92. I subsequently learned from B2 that his HcV treatment had involved some form of chemotherapy which had led to him having been rendered quite unwell, and additionally depressed, but I knew nothing of this at the time – he had kept it to himself throughout, told no one of the diagnosis and gone through Hep' C treatment and its side effects without ever having let anyone know.

93. I find it awful to think that he had gone through something so impactive without my having known, and consequently without my having been able to offer him any support. Looking back, I can remember having tried on a number of occasions to arrange for us to meet up, but I was always given some reason or another by him as to why this couldn't happen, so time passed without my having had any cause for concern. In reality, time passed as he was having treatment and didn't want anyone to find out, so he suffered alone.

94. Our parents were both alive when we lost B1. His death came as a most severe blow to them both as they had never envisaged losing one of their children, especially after the initial scare at the hospital in Reading. In their eyes he had haemophilia, thousands of people have haemophilia, it isn't fatal, or at least it shouldn't be, and parents *do not* have to bury their children.

95. I can recall having spoken to our father a few years after B1 died, and him telling me just how ill B1 had been before he died (when he had been living in B1, and he spoke of how both he and our mother had sought to shield us from what had really been going on – quite successfully as it

happened, as none of us really knew too much. They felt that it was their responsibility to look after B2 and B1 not ours, so they sought to keep us out of it and let the boys live as normal a life as was practicable, telling me that, *"Mum and I felt that it was our problem,"* but they failed to see the impact this may have had upon their other children as they were so caught up in their own 'nightmare' and couldn't see much beyond themselves once HIV/AIDS had been diagnosed.

96. Both of them were devastated by B1 s death, and I can remember my mother having told me that it had left a void in their lives, where something important was missing. She told me that the sense of loss even spread into everyday conversations where she not only found it difficult to talk about, but even to answer simple questions such as, *"how many children do you have?"* She told me that she simply didn't know *how* to answer - did she include *all* of her children, or just those that were alive? It made her feel very awkward.

97. Our mum had also been a very religious woman, following the Catholic faith. She seemed worried about B1 being able to have what she referred to as *"a good death,"* which I understood to be a fitting end for a Catholic. B1 had not been particularly religious, but prior to his passing he saw a priest and I believe that he managed to find some peace and acceptance of the fact that he was dying. He may have done this to appease our mother, or done it of his own account, but whatever his reasons were, he did it.

98. Mother had always 'fussed' over us as children, especially B2 and B1 once they had been found to have haemophilia, and B1 in particular following the bleeding episode in Reading.

99. As a parent, both mum and dad would do anything for us, and their approach didn't change even when B1 was hospitalised towards the end of his life, as she would still bring food and things in for him, even where he simply didn't want them, had no appetite, or couldn't even eat them – it was her way of showing that she cared, of doing something (she felt that she *had* to do something) for B1 without having to actually say anything. Often, B1 would refuse to eat her offerings, but it never stopped her fussing, or my mum and

dad caring and worrying about him – they just never spoke of it, it wasn't what we did, we kept it all to ourselves.

100. B1 's death also posed issues for his wife, especially as regards the funeral arrangements. GRO-B and B1 had wanted him to be buried wearing particular clothes and footwear, but instead he was apparently marked up as being a 'Category Two' body. I do not know what that meant, but clearly special arrangements had to be made for his disposal, as he was not dressed as requested but sealed in a body bag. Nor could he be buried as had been their intent, as like it or not, as someone who had been infected with HIV/AIDS he had to be cremated – family wishes were not taken into account, something which made dealing with his passing all the more difficult and upsetting.

101. Even at his funeral, the true cause of death remained a family secret, as none of us mentioned HIV/AIDS to anyone attending – as before, we each kept our own counsel, as not only did we not speak about it to one another, we didn't mention it to anyone else, for fear of exposure and concerns as to what people may think of B1 and how he had become infected. Hardly anyone amongst our broader family or friends knew the truth, and we were not going to tell them.

102. We also worried for his wife, and how the cause of his death becoming known may have impacted upon her. We even worried that it may have adversely impacted upon any life insurance policy he / she may have had.

103. His cause of death was formally recorded as having been due to a massive internal haemorrhage. This may perhaps also have been appropriate for a patient with haemophilia, but there was absolutely no mention made of either HIV or AIDS.

104. This meant that whereas the single event that served to claim his life may have been recorded correctly, the official record was and remains lacking as to the true cause. This is, that as a haemophilia patient, B1 contracted HIV/AIDS because of his treatment with contaminated Factor VIII, and that it was AIDS that had led to the haemorrhage.

105. B1 had told GRO-B that he had cancer, which was a deliberate lie on his part, but which allowed him to mask his true condition from employers whom he feared would take a poor view of the situation and he'd either not be given, or stood to lose, his job. Towards the end, he told them of his true status (HIV/AIDS), and rather than find them taking inappropriate action B1 found that GRO-B were extremely supportive, paying some of his bills, providing him with a mobile 'phone, and that they even asked him *why* he hadn't told them before?

106. I do not know how my younger brother GRO-B was affected by what took place, he was younger than I and as such his experiences may have been different, but as he is also providing the Inquiry with a statement he will no doubt be able to speak of this himself. However, I do know that it had a major adverse impact on the life of my younger sister GRO-B who rather went off of the rails following B1's death.

107. Having been that much younger, GRO-B had spent far more time with B1 around our family home than some of the rest of us and they were quite close. GRO-B had been in India, travelling when B1 had finally become unwell, but cut her trip short and came home to help care for him, so her plans went completely awry.

108. Just five years after B1 died, we lost our mother. GRO-B was still grieving for the loss of B1 and struggling to come to terms with his death and its circumstances, when mum passed away adding to her grief. Taken together, these events had a major impact upon her and caused a lot of concern for the rest of us as to her health and welfare.

109. She changed a lot in terms of her personality, and would frequently 'disappear,' taking herself off without anyone knowing where she was going, how long for, or why. I find this very hard to describe, but it was a source of real worry for me, and was all part and parcel of our dealing, or not, with B1's death.

110. For my part, I was in a state of shock for some time, and my not having spoken to anyone about it all didn't help. Looking back, I now find that I have

excluded certain memories, deliberately blocked them out as being too painful to recall, and when I look at old photographs, I sometimes struggle to remember the events they represent.

111. Following my mother's death, I went into social work, and whilst living in Wiltshire became a volunteer with the GRO-B – a charitable organisation providing assistance and advice for people with HIV/AIDS, together with their families and friends. I realised just how significant and impactive an HIV/AIDS diagnosis was, and the importance for those affected to receive counselling and other supportive measures at the earliest opportunity.

112. HIV/AIDS impacts heavily upon family relationships and friendships, as it can often be very difficult for people to confide in one another, to be open with one another, or to support one another where they do not understand what may be going on – in terms of either the medical position, or the emotional one or just appreciate why people act as they do.

113. When my brother was found to have developed AIDS, and I sought to confide in my husband (now my ex-husband), although he wanted to be supportive of me, this proved difficult as he simply couldn't understand my concerns or actions (e.g. the research conducted) as it was not *his* brother who had the condition. It impacted differently upon me than it did upon him.

114. Perhaps as a consequence, although I had promised that I would tell no one, I went against B1 s wishes as I confided in a friend, someone whom I swore to secrecy, but to whom I turned as I felt that I needed to speak to someone about it. It made me feel extremely disloyal, and guilty for having done so, but I needed support and felt that I had nowhere else to turn.

115. Towards the end of his life B1 confided in me that his one regret was that he hadn't had any children with GRO-B He told me that this had been a deliberate decision on their part, as both feared that HIV/AIDS may have been passed on to any child they had.

116. Once B1 had passed away, the true impact of his death became apparent with his widow, someone who having since remarried twice, both

times unsuccessfully, is sadly now an alcoholic. She had lost the man she truly loved and appears to have sought an alternative, but having failed to find one, resorted to drink for comfort. It is a very sad outcome for someone who had stood by B1 through thick and thin, and had chosen to marry him even though she knew he had HIV and as such, only had a short life expectancy.

117. Of more recent times, his widow has told us that she no longer wants to have anything to do with B1 or what happened to him, and has decided to no longer consider herself to be his next of kin – a position which has passed to B2 as a direct consequence. As a result of B1's infection and subsequent death, her life has changed dramatically from her first having met B1 at GRO-B

Section Six - Treatment / Care / Support

118. Once diagnosed as having AIDS, B1 was offered the services of a trained counsellor through the Terrence Higgins Trust, another charitable organisation seeking to assist people with HIV/AIDS. He was helped by a counsellor called Graham whose assistance he found very helpful.

119. I do not believe that the provision of psychological support should have fallen upon a charity to provide, but that it should have been provided as a matter of course by the NHS to those affected. This would, and should, have included B1's broader family, his wife, my siblings and I, and our parents as an example.

120. Families do not always discuss bad news and medical problems, so individuals are often left to cope alone, even if they are members of a large group – I feel that you can find yourself very lonely in a crowd, especially when dealing with something new, something awful, so some timely professional assistance could go a long way.

Section Seven - Financial Assistance

121. I believe that B1 received some form of financial assistance prior to his death, something in the region of £32,000- but it was not referred to as

compensation, and in no way offered compensation at a level commensurate with his suffering and subsequent loss of life.

122. I understand that B2 is either currently in receipt of regular payments as a result of his infection and its cause, or is due to receive regular payments for the same. None of our broader family have ever received any financial assistance or compensation, and our parents are now both sadly deceased.

123. Money would not have brought B1 back, or eased B2s suffering, and my providing this statement is not about the money currently being debated as compensation payments for people affected in these ways, but if compensation payments are to be made then they should adequately reflect the pain and distress caused. £32,000- for my brother's life is and was insulting.

Section Eight - Other

124. I truly hope, that by providing the Infected Blood Inquiry with a statement, that I am in some way contributing to the means through which something like this can be prevented from ever happening again. If any action can be taken to prevent any repeat, it needs to be undertaken as soon as may be possible to avoid any further avoidable loss and suffering.

125. In my view, the situation is all about honesty, and there needs to be a far more honest approach to the NHS treating people, accompanied by transparency as to how that treatment is to be delivered, why, and to what end and this should extend into the nature of any materials being used and their origins together with any associated known risks. All patients should be adequately informed.

126. Prior to the contaminated blood scandal, a major issue arose with Thalidomide and life-long disability impacting large numbers of patients. Here, perhaps because those concerned happened to be nursing mothers and their children, there was a great deal of public sympathy. Sadly, with HIV/AIDS and HcV, there has been little or no sympathy beyond the families and friends of those affected, a sad situation driven by negative publicity, adverse media coverage and resultant public fear. More needs to be done when these crises

arise to present a balanced view of what may be happening, and provide appropriate care and sympathy to avoid those affected being discriminated against.

127. Having asked for counselling to be made available, and offered to a broader range of people than just the patients concerned, I should add that this needs to be delivered by trained professionals with experience and knowledge of the ailments that rest at the root of the problems someone may face – there would be absolutely no point in placing a patient with HIV/AIDS before a counsellor with no knowledge or experience of HIV/AIDS, as the patient would very quickly identify this shortcoming, and disengage.

Statement Of Truth

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

Signed: GRO-B

Dated: 25/4/2023