Anonymous

Witness Name: GRO-B
Statement No: WITN5607001
Exhibits: Nil
Dated: 17 February 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 20 April 2021.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1972. I reside at GRO-B GRO-B I married my late husband GRO-B: H H ("H") in GRO-B and we have two daughters together. I am currently not employed. I remarried in GRO-B but I still remain GRO-B. I did not wish my daughters to have a different last name.

2. I intend to speak about my late husband H's infection with HIV and Hepatitis B ("HBV"), after having received Factor VIII blood product at the Northampton General Hospital, when he was fifteen years old. In particular, I wish to discuss the nature of how he learnt about his infections, how his illness affected him and our family life thereafter, and the financial assistance we received. H's date of birth is GRO-B 1967, and he died on GRO-B 2010. Before his death, he was employed

as a manager at a hairdresser's wholesalers, before he lost his job when he was forced to take early retirement due to his HIV infection.

3. I can confirm that I am not currently legally represented and that I am happy for the Inquiry Team to assist me with my statement and that the Inquiry Investigator has explained the anonymity process to me. I wish to remain anonymous due to personal reasons, to protect my children and because this is what H would have wanted.

4. The Inquiry Investigator has explained to me the 'Right to Reply' procedure, and I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.

5. I wish to acknowledge that naturally as time passes, memories can fade. I 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.

6. I have constructed this statement without access to H s medical records.

7. My friend GRO-B was present in the room during the process of drafting my witness statement and in supporting me and she has been able to provide some information surrounding H s life and our family unit.

Section 2. How Affected

8. In 1982, my family moved from GRO-B to GRO-B Then, in 1988, I met H through the hairdressing trade. My boss was the partner of his best friend, so he used to come to my workplace on a Friday afternoon. Thereafter, we formed a romantic relationship, and we got married in GRO-B

9. As far as I am aware, H was diagnosed with severe haemophilia when he was a toddler, as a result of experiencing a number of bleeds and bruising. Prior to his birth, his mother knew that she was a carrier of haemophilia.

10. Thereafter, from the point of his haemophilia diagnosis, H received treatment for any bleeds he experienced at the Churchill Hospital ("Churchill"), Old Road, Headington, Oxford, OX3 7LE. Initially, H received Cryoprecipitate, whereby he would attend the Churchill to receive treatment. His treatment was then changed to Factor VIII. He was taught how to self-administer his Factor VIII himself at home, without having to take the trip to Churchill. H received treatment with Factor VIII throughout his life, and until the date of his death.

11. Around 1982, when H was approximately fifteen years old, he experienced an accident when he fell off his bike and broke his collarbone. He was immediately taken to the Northampton General Hospital ("Northampton General"), Cliftonville, Northampton, NN1 5BD, to receive medical treatment. As a result of blood lost, he was provided with two bottles of Factor VIII blood product.

12. As far as I am aware, neither H or his parents were provided with information or advice beforehand, surrounding the risks of being exposed to blood borne infection as a result of receiving Factor VIII blood product.

13. Around 1984, when H was aged approximately seventeen years old, his parents received a telephone call from the Churchill. They were asked by one of the doctors whether they could attend the Churchill so that H could undergo a blood test.

14. Within a short period of time, H and his parents attended the Churchill for a face-to-face appointment with Dr Rizza and Dr Matthews. They were told that it had recently come to light that certain batches of Factor VIII had been identified as having been contaminated with blood borne infection. They were also told that as result of action taken, two bottles of Factor VIII, which H had received at the Northampton General when he was fifteen years old, had been identified as having been implicated with HIV.

15. Thereafter, H and his parents agreed for a blood sample to be taken, so that a confirmatory blood test could be performed. Within a short period of time, H was

told that the test result had returned, and that his blood had tested positive for the presence of HIV.

16. As far as I am aware, I do not believe that H nor his parents were provided with adequate information surrounding his infection, which would have otherwise allowed them to have understood and managed his HIV. I also do not believe that they were provided with adequate information surrounding the risks to others as a result of his infection. He was simply advised of the risks of sexual intercourse and blood to blood contact. He was given a large box of condoms to practice safe sex.

17. When H was about 21 years old he was told by Dr Rizza, that his life expectancy would be around fifty-years-old.

18. H was very on the ball with regards to the risks posed to others resulting from his HIV infection. He made sure everything was separate, such as toothbrushes and towels. He also made sure the girls did not come into contact with his blood. He also didn't let the girls come anywhere near him when he was administering Factor VIII blood product.

19. I believe there to be only one cause of H s HIV infection. This being the two bottles of Factor VIII he received at the Northampton General when he was aged fifteen years old, following an accident when he fell off his bike and broke his collarbone. This belief is attributable to information H and his parents were given by Dr Rizza, that the batch numbers of the two bottles of Factor VIII he had received had been traced back to an infected donor.

20. As previously stated, H and I met in 1988, when I was aged seventeen years old and he was around twenty-one-years old. It was not until we had been dating for around four to six months, that H sat me down to tell me something that had been on his mind. I remember him being anxious before telling me.

21. H had said that he had something to tell me, and that one of the nurses called Mary Fletcher had been putting pressure on him to tell me before our relationship became too serious. I immediately knew that he needed to tell me something which

was bothering him, as he could not sit still. He stated something along the lines of, "*Look, I have to tell you something, but I expect you to walk away so I will take you home when you are ready.*" In response, I looked at him puzzled. He said, "*You know that I am a haemophiliac? Well at the age of fifteen, I came off my bike and broke my collarbone. I was taken to Northampton General and I had to have two bottles of Factor. They then tried to move my collarbone which you cannot do if you are a haemophiliac.*"

22. It felt that H was 'skirting around the houses' with regards to what he needed to say, so I asked him, "*What has this got to do with anything?*" In response, he told me that, "*The Factor he was given had been was infected with HIV.*" I broke down crying. I did not know what to say.

23. When H was about 21 years old he was told by Dr Rizza, that his life expectancy would be around fifty-years-old.

24. H wanted to take me home, but in that instance, I did not want to go home. I had said that we needed to talk about it so that I could understand. I was only seventeen years old at the time, and I did not really know what his diagnosis meant with regards to its potential life-changing implications. At such a young age, you do not think about having children or the future, but despite H and I being very new to our relationship, I was already falling in love with him. I told H something along the times of "*I understand. Yes, our life is going to be very different, but it makes no difference to me.*"

25. H was very worried about telling my family. He offered to tell my family himself, but I believed that we should tell them together. I just needed time to get my head around the information I had just been told. Thereafter, H drove me to my family home.

26. That night, I sat with my dad, and he could tell that there was something wrong, so he asked what was bothering me. I told my dad about H In response, he just put his arm around me and said "*he is a good chap, you'll be fine. He will look after*

you." I decided to tell my dad there and then without H being there as he could tell there was something wrong with his daughter.

27. Thereafter, H and I got on with our lives. We got engaged, and we got married.

28. H regularly attended the Infectious Diseases Unit at the Churchill for face-to-face appointments with his Consultant Chris Connolly. He was prescribed with a 'cocktail' of drugs for his HIV, and would regularly attend check-up appointments.

29. Before he went on to oral medication for the HIV infection he was given medication via a drip, which used to take an hour to go through and he was on that once a month. The drip treatment lasted for around 2 years. Once his CD4 count went up that is when they decided to start introducing oral drugs which had been newly developed.

30. When H was in his thirties, he experienced periodic bleeds which meant that he had to inject himself with Factor VIII three times a week.

31. Up until around 2003, H would go to the Churchill to collect his Factor VIII. However, in 2003, his treatment began to be delivered to the family home. H was very adamant that he did not want his treatment to be delivered to the house, as at the time, we lived in a small village and we did not want the neighbours to talk. He complained to the Churchill, but he was told that this was now standard practice. It wasn't so much the Factor treatment it was more the big Sharp boxes, they couldn't send a smaller Sharp's box because H was on 2 bottles of Factor 3 times a more which obviously could be more if he had a bleed.

32. In February 1993, my best friend GRO-B and I were both pregnant at the same time. I was pregnant with twins, but unfortunately, I suffered a miscarriage. I had lost one of my twins, and the medical professionals believed that they could save our other child. In the end, we lost both of our children. This hit H in particular, as he blamed himself for what had happened. At the time he thought that it was because his sperm was inadequate. I was scared of it going wrong again and I put off trying to conceive.

33. However, later in 2000 I gave birth to our first daughter and our second daughter was born in 2007. So we ended up with our two beautiful girls.

34. In the lead up to H s death on GRO-B 2010, from the outside world looking in, it did not appear that his HIV infection had much of an impact on his physical and mental state of health. However, behind closed doors, he was experiencing a number of side effects associated with the medication he received for his HIV. This is discussed further in **Section 5** of my witness statement.

35. On GRO-B 2010, H our girls, and I walked to our local supermarket as H had run out of paracetamol. For a period of six months prior to this, he had been experiencing enhanced headaches. However, it was not unusual for him to have headaches, as they were often a side effect of the medication he was prescribed. H went into the supermarket with our eldest daughter before we all returned home. It was a normal Friday evening. I recall H being particularly happy as the GRO-B was on the television as he loved GRO-B He never complained about his headache again that evening, we stayed up and watched a film until about 1.00am and then we went to bed as normal.

36. On GRO-B 2010, I was awoken by H being sick, which was not unusual due to the medication. He complained about his headache again and I told him to take 2 more paracetamols and go back to sleep. H was experiencing a particularly bad headache, which I thought was typical as we were due to go on holiday within a few days. In response he stated something along the lines of, "*I can't go to sleep. If I go to sleep, then I won't wake up.*" I told him to stop being so silly and to just go to sleep. I will never forget those words as they were his last words.

37. Around 07:30am on GRO-B 2010, I got up to attend to our youngest daughter who was only 3 at the time, and I recall H still lying in our bed. Then, around 08.45am, I went back in and saw that H was slumped over the side of the bed. His top half was slumped with his hands and head on the floor but his waist downwards was still in the bed. He must have tried to get up as there were no sheets on him and he had wet himself. My eldest daughter and I tried to move him back on to the bed,

but he was a dead-weight. He kept a torch on his bedside table, so I picked up the torch and shone it in his eyes. His pupils were completely black. I remember my eldest daughter throwing some water at H to try to wake him up but he didn't move.

38. I called for an ambulance, and he was taken immediately to the Northampton General. In the ambulance they put a catheter in his hand but he didn't move. I could see that the veins on the side of his head were very raised.. I also remember that his breathing was rattling. One of the paramedics attending to H asked me if his breathing had ever been like this before and I remember asking her if it was the 'death rattle' to which she told me it wasn't, but I knew that it was.

39. Upon reaching the Northampton General, the doctors rushed him into a side room and placed him on a life support machine. At one point, one of the doctors took his parents, my parents, and I aside, and told us that H had suffered a brain embolism, and that he had more or less passed away, but the life support machine was keeping him going. In response, I said to my dad "*please don't take him away.*" I begged the nurses and doctors "*please don't take him away from me.*" I recall one of the nurses asking me to tell them when I was ready to turn his life support machine off, but when was I ever going to be ready? I did not want to be the one to end his life by telling them to turn off his life support machine.

40. I looked at H and I could tell that he had already gone, but the machine was keeping him alive. I plucked up the courage to tell the nurse that I was ready. H died within a matter of seconds, on GRO-B 2010, at the age of forty-three.

41. Then one of the nurses came into the room where we were all sitting with H and told us that as his death was 'sudden,' and despite his HIV, HBV and haemophilia, the police would need to be called as matter of standard practice. The nurse then stated that you could get good and bad police officers, and told me to be prepared. My father responded stating that if an arrogant police officer came to the hospital, then he would be likely to get arrested given what his daughter and son in law had been through.

42. Within a short period of time, a young police officer named Luke Cousins attended the Northampton General, and he could not have been nicer. I remember one of the doctors speaking to him before he came to speak to me. The first words he stated were, "*I am really sorry for your loss. How old are your girls*?" He had also stated that he felt for us, and wondered how we had coped. After he had filled out the necessary paperwork, he gave me his card. He told me that I could ring him at any point if I needed him.

43. After H's death, I attended the Churchill for an appointment with a nurse named Lara. I told her that in retrospect, I now question whether I should have taken more notice that H was experiencing a headache as he was a haemophiliac. It should have rung alarm bells in my head, but at that time, it was not uncommon for him to have experienced headaches. The nurse reassured me that I couldn't have done anything, as it was quite common for haemophiliacs who had been taking a number of medication drugs to develop a brain embolism.

44. H's death certificate which is dated GRO-B 2010, states the cause of death as:
"I(a) Large Intracerebral Haemorrhage
(b) Haemophilia
II HIV +, Hepatitis B."

45. When I read H's cause of death, I was hysterical. I knew how much H hated being labelled with HIV, so I asked my father to call the coroner to see if it could be altered. The coroner was really apologetic but stated that unfortunately it had to be on his death certificate because those were the causes. Thereafter, for years and years, I have never had a copy of his death certificate in the house because of the girls. Instead, my father had a copy of H's death certificate at his house.

46. H did not like to talk about his HIV, or about death, so when he died, I did not know whether he wanted to be cremated or buried. To this day, I do not know whether I had made the right decision as to his wishes.

47. On the day of H's funeral, the hearse pulled up outside our family home. We had a high wall and I couldn't see the hearse arrive but I immediately heard the breaks

squeaking, and in response I said to my brother, "*that is H*" They wondered what I meant by this, to which I said, "*that is just something he would do.*"

48. H had once said that he hated to see coffins without flowers, so when he died, he had so many flowers that they had to put on another car as they could not fit all of his flowers in the one car. The girls wore cream dresses and tiaras as he called them his little princesses.

49. During the funeral service, I knew that H was looking down on us all. I had planned on playing our wedding song, 'Three times a lady.' However, by some coincidence, our wedding song would not play. It had been playing all morning, but at that instance, it would not play. H also hated wasps. During his funeral service, I noticed that there was a wasp that circled around his coffin, but did not land on the flowers. In addition, H always used to whistle. All of a sudden, our youngest daughter started to whistle, she was only 3 years old. She looked at the Order of Service pamphlet with H s photo and said to her Grandad, "That's my dad."

50. H s ashes are now buried in the church yard closest to our family home. This was a decision taken as the girls wanted to be close to their father, we wanted him home. On reflection, I wish that we had scattered his ashes in GRO-B Devon, as this was his favourite place. He had once said that he wanted to move our family to this area, but due to the lack of haemophilia services in Devon, this could not happen logistically. I remember him saying that he would end up in GRO-B and that his spirit would end up there one day.

Section 3. Other Infections.

51. Around 1995 to 1997, during a face-to-face consultation with one of the Consultants at the Churchill, H was told that news had come to light that he may have received an implicated batch of Factor VIII, which had been contaminated with Hepatitis. On hearing this news, H said something along the lines of, *"There is no point you telling me all of this as you have already told me that I have HIV. I have got that, no matter what happens, whether I have HBV or not, I am going to die. I have already to a life sentence."*

52. H was then asked whether he would provide a blood sample, so that a confirmatory blood test could be undertaken.

53. It felt as though we were waiting for a very long time for the results of the blood test to return. However, within a short period of time, H received a telephone call from the hospital whereby he was told that the result had returned, and that he had tested positive for the presence of Hepatitis B. H s response was very accepting. He had stated something along the lines of "*Oh well, another thing to add to my list. What can I do*?"

54. Thereafter, no treatment for his HBV was ever discussed. He was simply told that he had hepatitis, and that the risks were the same as HIV. In a way, his HIV diagnosis had taken precedence over his HBV diagnosis. They seemed to say you just have to get on with it.

55. In addition to HBV and HIV, around GRO-B or GRO-B 2010, shortly before H s death, he received a letter which I think was from the Department of Health. The letter stated that he was at risk of having contracted vCJD, as he had received a batch of blood which had been identified as implicated. In response, as a coping mechanism we laughed and made a joke of it. We wondered what else was going to be thrown at us. HIV, HBV, and now vCJD. Anything else?

56. Nothing ever came of this letter, as within a matter of a couple of months, H passed away.

Section 4. Consent

57. As far as I am aware, H was not never treated or tested without his prior consent having been obtained, nor without his knowledge, without being given adequate or full information, or, for the purposes of research.

58. I believe that when H was a child, his parents would have provided consent on his behalf to anyu testing and treatment he would have received in the

medical setting. Then, when H was an adult, I believe that he would have provided consent himself.

59. Whilst I believe that his parents would have provided consent to H receiving Factor VIII as treatment for his haemophilia, surrounding the time he was infected with HIV and HBV, they were not advised surrounding the risks associated with blood borne infection, which would have otherwise allowed them to have provided fully informed consent. This would have allowed them to have made an informed decision on whether to provide H with the treatment.

60. At no point was I ever advised by a medical professional that I should undergo a blood test for the presence of either HIV or HBV, I did this off my own back. When the result of the blood test returned, following my miscarriage, I was told that I had tested negative for the presence of HIV and hepatitis. I think the HIV test result came back quicker than the HBV test (within 7 days) as it was normal for the HBV result to take longer to come back.

Section 5. Impact.

Mental/Physical Impact

61. From the point at which H was diagnosed with HIV, he was provided with a number of medication drugs as treatment. These drugs came with a number of associated side effects. Therefore, whilst H had experienced a slow deterioration in his physical state of health following his HIV diagnosis, it is difficult to determine what is attributable to his medication or effects of the HIV itself. Therefore, I cannot state as fact the exact physical impact of his blood borne infections on H

62. Nevertheless, when H was in his mid to late thirties, a large lump gradually grew on the back of his neck. H sought medical assistance surrounding his lump, but he was told that this was attributable to the combination of the drugs he was given for his HIV. Also, that nothing could be done medically about

reducing the lump. It was very pronounced towards the end and he tried to cover it up as much as he could. It pushed his head forwards.

63. Another side effect of H s HIV medication was achy bones. However, as he had developed arthritis as a result of the effects his haemophilia had on his body, it is difficult to differentiate between the two.

64. H also developed thrush in his mouth and he suffered periodically from this. However, in the last 2 years prior to H dying he didn't suffer from thrush so much because his CD4 levels were higher. H had pneumonia in the year before he died. He was given treatment of 2 lots of anti-biotics for 6 weeks, he was given a higher dose for 4 weeks and they lowered the dose for the remaining 2 weeks. He underwent testing on his chest with X-rays at Northampton General. He refused to stay in hospital because that was where he was infected and he always used to say that he didn't want to die in Northampton General.

65. With regards to the physical impact his HBV diagnosis had on his state of health, if H had too much cheese or red meat, he would feel sick and would turn yellow in complexion and would suffer discomfort. He was told that this was attributable to the HBV having an effect on the condition of his liver.

66. My friend GRO-B remembers his face was once strawberry coloured as a result of the medication he was on. I also recall that he had white heads on his back but over time these went.

67. I cannot say that H had ever been formally diagnosed with cirrhosis of the liver. He did undergo a number of biopsies which had shown that he had fatty tissue of his liver. Towards the end of his life, the Churchill wanted to do a further liver biopsy, but this procedure did not go ahead as H didn't want it as there was nothing they could do for his hepatitis and he didn't want to be messed about with. He was more worried it might trigger things off. It was more for them to monitor his liver for any deterioration as it had been quite a few years since his last biopsy.

68. I believe that H s HIV and HBV infections had an impact on his mental state of health. Behind closed doors he would get very down, I do not know whether this was as a result of the treatment, or as a result of the realisation of his future. However, to the outside world he put on a brave face and no body would have known anything was wrong.

Treatment

69. Following H s HIV diagnosis in 1984, he was offered Zidovudine (more commonly known as azidothymidine, or AZT) at the Churchill. However, due to the bad associated side effects, he did not take his consultants Dr Rizza up on his offer of this treatment.

70. For a long period of time when H was in his thirties, he had undergone combination therapy for his HIV. This consisted of three oral drugs which he had to take at very regimented times, 8:00am; 04:00pm and again at 08:00pm. Whilst his treatment made him very nauseous and lethargic, it had an initial positive effect on his CD4 count, so he continued with this course of treatment. The treatment was to stabilize his HIV infection. He regularly attended a check-up appointment at the Churchill with Chris Connolly and John Warring, every six-months.

71. I remember that GRO-B was born at three minutes past four in the afternoon and H had to go to the car to take his tablets which he was late in doing due to the birth. As a result he was violently sick in the car and I was getting worried because he hadn't come back.

72. They changed this treatment about 7 or 8 months after my daughter's birth as it began to affect his vision. He was pleased because his treatment was reduced to one tablet a day. However, this didn't work and Chris Connolly changed his treatment again. In a period of 2-3 years he had quite a few different tablets. When his CD4 levels started dropping they would try

something else. His check-up appointments were changed to every three months.

73. By the time he died he was on 4 tablets a day; 2 in the morning and 2 at night. His CD4 levels were dropping all the time and had dropped down to 420. I remember Chris Connolly saying if it dropped any lower the next time they would have to try a combination therapy again, but it never came to that because H passed away. His next appointment was in the GRO-B but he died in GRO-B

Impact

74. H s HIV and HBV infections had a huge impact on him from the point of his diagnosis. He had good and bad weeks, but for the majority of the time, to anyone on the outside looking in, he had the appearance that everything was 'okay.' At his lowest point, he had told me that he was not going to die like the other HIV patients he had seen at the Churchill when he attended for regular appointments. He said that if he ever got that low with regards to his physical and mental state of health, he would just take himself off in his car and put it into drive and end his life. I told him not to be silly and to think of his girls.

75. I often think, he was only fifteen years old when his life had changed forever. How did he cope? He went through so much in his life, and he did not let anyone know. Until the day he died, no matter how much he was hurting, he had a smile on his face. Everyone loved H, he was one of a kind. He would do anything for anyone. There will never be anyone else like him, he had a heart of gold.

76. His HIV and HBV infected status also had an impact on our marital relationship. We had our ups and downs due the pressures faced, but we always got through it. We met when we were both very young, so we grew up together. Throughout our lives, there was always a hurdle to jump. We were never apart, and we dealt with things together. Obviously, it also had an impact on the physical side of our relationship too.

77. On GRO-B 2010, I lost my life, I lost everything. We were together for twenty odd years. There was a lot of heartache and worry, both financially and physically, but he gave me the best twenty odd years of my life. No one can give me that, it is impossible. He was one of his own, and he was never ever down. His motto was "*Life is too short, and one day I will not be here. I just want you to have a smile on your face*."

78. Eleven GRO-B years after his death, I miss him very much. I miss his laughter, and his smile. As the years go by, you forget what the little things looked like, but he was and will always be the love of my life. They say time is a healer, but it never really gets any easier. It has made me become a lot tougher now, as I do not want to be put in that situation again. I think it has made me a much stronger person.

79. Whilst I have now remarried, technically, I never divorced H as he was taken away from him. Whilst no one will ever compare to H I believe that he sent my current husband GRO-B to us. I have told GRO-B everything about H as I did not want there to be any secrets. GRO-B has been a rock for my girls and I.

80. Our daughters were both of a young age when their father passed away. Our eldest daughter GRO-B was only ten years old, and our youngest daughter GRO-B was only three years old.

81. With regards to my eldest daughter, it was difficult for her to have understood that when I went into the Northampton General with her daddy on the day he died, that it was only me that was going to walk out.

82. Her father's death hit her particularly hard five or six years on down the line. When she was aged around fifteen or sixteen, she went into a dark hole. We went on holiday to GRO-B Devon and took my oldest daughter's boyfriend at the time, with us. This was the place we always used go to on a family caravan holiday with H before his death, so it meant a lot to us.

83. One day, I woke up at 06:00am. To this day, I do not know what woke me. I went to see whether my daughters were awake, and to my surprise my eldest wasn't there. I asked her boyfriend where she was, to which he said he thought he knew where she was.

84. There was a cove in GRO-B where H had once said before his death, that one day he would like to be, similar to Captain Jack Sparrow from the Pirates of the Caribbean as my daughter loved that film. She tried to take her own life that day on those rocks so that she could be with her dad.

85. I got GRO-B some professional counselling and she got through it.

86. The only way for GRO-B to have understood that her father's death was not her fault was to tell her the truth about his HIV and HBV. I told her everything, and we got there in the end. It was tough. Thereafter, she completed two charity events for the GRO-B There is currently a plaque GRO-B in H 's memory as a result of GRO-B raising so much money.

87. With regards to my youngest daughter GRO-B she was only three years old when she lost her father. How do you tell a three-year-old that her father is never coming back? We had to tell her that her daddy was up in the sky, flying all the helicopters. Thereafter, whenever she would see a helicopter in the sky, she would point and say "*that's my daddy*." When GRO-B started primary school, one of the teachers told me that on one occasion GRO-B had stood at the window and said, "My daddy is in that field."

88. GRO-B was always aware of her father's haemophilia, but we have only recently told her about her father's HIV and HBV infections. At the time she was too young, but as she is now of an age where she could fully understand the information, I thought she should know as I didn't want any secrets. It was always like having a dark secret and it shouldn't be like that. She does not have the memories with her father that her older sister has, which on some days is hard for her to comprehend.

89. H has missed out on so much of our daughters' lives. He missed seeing our oldest graduate, pass her test, and seeing our youngest grow up. I had previously thought did I do right by having the girls? Deep down we always knew that H was going to die, we just did not know when. It is not just about H but also about our daughters. Was I being selfish by having the girls when I knew that he was going to die? However, now that I do not have my H in my life, if I did not have those girls, I believe that I would have taken my life. I did not think that I could ever live without him, and I do not believe that I would be here today without my girls.

90. I believe that H s HIV and HBV infections had an impact in the development of his mother's dementia. I believe that her dementia was brought on by his death as it began two years following his death. She had thought that if she had not been a carrier of haemophilia, then he wouldn't have needed to receive Factor VIII, and he wouldn't have got HIV and HBV.

91. I believe that both H and I have experienced the stigma attached to HIV in particular, on a number of occasions.

92. Before I knew my best friend GRO-B we lived close to each other. GRO-B has since told me that her and her husband GRO-B saw H and I on a number of occasions, and wondered what we did as we never went out of our house. Then, one of her friends had told her that her cousin had recently got married, but the bride was a gold digger and the groom had HIV and that she had married him for the HIV related money. She had also said that the medical profession had told the groom that he needed to measure his coffin in preparation for his death. GRO-B did not know the identity of the bride and groom at the time.

93. H and I purchased a puppy, and it was the puppy that caused GRO-B and I to click as GRO-B also had a young dog. From then on, we were best friends. GRO-B had visited our house for the first time shortly after getting the puppies, and during conversation, I showed her our wedding album. GRO-B had asked where H and I got married, to which she stated that her friend had told her that

another couple had recently got married at the same venue, and that the groom had HIV. At this point, GRO-B did not know that H and I were the bride and groom. But, as she said this information, H and I looked at one another in shock. We were sitting behind GRO-B as she looked at the album.

94. The next day, H and I went to knock at GRO-B and GRO-B's door. H had said to GRO-B and GRO-B that he was not going to come into the house, as he had to tell them something. It was here that he revealed that the bride and groom she was talking about the day prior to our visit, was in fact, us.

95. H was aware that around that time, the stigma attached to HIV was prevalent. The fear attached to the blood borne infection was also heightened, and a lot of people were ignorant to the facts surrounding how HIV could be contracted. It was automatically assumed that if you had HIV, you must have been a drug user or a homosexual. People were not educated that people could contract HIV through no fault of their own.

96. We did not know GRO-B and GRO-B too well at that period in time, so we did not know how they would receive the news. Luckily, they did not care about H's infection. They were accepting of him, threw their arms around him, and treated him as if nothing had changed. We have been inseparable ever since.

97. Thereafter, we realised that a number of H's family members had been discussing his HIV diagnosis. It was only my parents, his parents, his sister, and our best friends, GRO-B and GRO-B who knew about his HIV infection. It was kept very close to the family due to the associated stigma. Therefore, when we had become aware that a member of the family was telling people stories which were all lies, we got a solicitor involved to prevent the individual spreading further lies which could have destroyed our lives.

98. H's HIV and HBV infections had an impact on our social lives. We lost a lot of friends as we were worried that they would ask questions. It was really tough. When I think about it now, it was hard work.

99. In addition to the above incident, before we were married H experienced the stigma attached to HIV when he was a teenager, shortly after he found out about his diagnosis. He attended the GRO-B Hospital in Oxford to receive dental treatment with his mother, where he was put in a side ward following his dental treatment, which had a large red cross placed on the door with the words, 'Do not enter'.

100. H was unable to attend our family doctors' surgery because he was worried that someone would become aware of his HIV and HBV infections and that this would inadvertently impact on our girls due the associated stigma. His whole life was about protecting me and our girls, so if anyone found out, it would disrupt our whole lives. So he remained with his surgery and the girls and I registered at our local surgery. We couldn't even be at the same practice as a family unit due H s fear of people in the community knowing about his HIV infection.

101. H s HIV and HBV infections had a work-related and financial effect on us and the family unit. H was previously employed as a manager at a hairdresser's wholesalers. In around 1991, GRO-B he was off work for long periods of time as he was on treatment for his HIV. As a result he was in receipt of statutory sick pay. Due to his extended periods of absence, his boss started to question his state of health. He was asked to submit himself for a medical assessment, which he knew would include a blood test. He felt as though he had been backed into a corner, so he had to tell his boss about his HIV infection.

102. In response to H telling him about his diagnosis, his boss's response was that he was sorry and he commented, *"You don't look like a person with HIV."* H replied, *"What does a person with HIV look like - death?"* At that point, H was let go. His boss's words were, "*For your health reasons, you would be better off taking early retirement and being at home in your situation."*

103. Thereafter, H was in receipt of income support and higher rate Disability Living Allowance and luckily we resided in a counsel property. He wouldn't have been able to get a mortgage anyway because of his HIV status.

104. H was in receipt of a mobility car through the Mobility Scheme 'Motability'. This meant that he was able to get a new car every three years. When H passed away on GRO-B 2010, the Scheme wanted his car back the next day because he was buying it and because he got the finance through them. In response, I told them that they were not going to have the car as it was H s car, it meant so much to him. I had only just lost him. They told me that if I was not going to give the car back then I would need to find £3500 within 7 days. After numerous conversations over the telephone between my father and the Scheme, they gave me until the end of GRO-B 2010 to find £3500. H had bought that GRO-B and he loved it, normally he would renew his car every 3 years but he wanted to keep this one and we had a personalised number plate. I wasn't going to let them take the car off me!

105. Due to H s HIV, HBV, and haemophilia, we were unable to obtain a mortgage, or get life insurance.

106. H the girls, and I were not unable to go abroad, as when the airport security would see his Factor VIII, they would either question him, or take it off him. Thereafter, we continued to go on holiday to GRO-B Devon. We could never go to America and H used to get really angry about that as it was America that gave him HIV. That really did frustrate him.

Section 6. Treatment/Care/Support

107. I am not able to fully comment as to whether H was provided with adequate treatment, care and support in consequence of being infected with HIV and HBV. My personal opinion with regards to Dr Rizza and Dr Matthews was that H and his parents would have been supported, this is my personal opinion, because they were like your typical family doctors who knew you and bearing in mind they had known H since he was a baby. The Oxford Haemophilia Centre at the

Churchill Hospital back in the early 1990s, when both the doctors were there, was a very close-knit unit. However, when Paul Giangrande joined the unit it had expanded and it changed, with a big new extension along with the new John Warin ward and as a result it became more like a normal NHS hospital. H and I didn't warm to Paul Giangrande at first, as we felt that he had an abrupt nature, however, over time he was great and H grew to trust him. He was so helpful with everything and even after H had died. He came to H's funeral along with Sharon Osborne who was part of his team from the Admin side. We also had flowers at the funeral from the Haemophilia Centre.

108. I have nothing but good words to say about his Consultant Chris Connolly from the Infectious Diseases Unit at the Churchill. He was always very caring and kind to H and went above and beyond to meet his needs.

109. I don't believe that H's infected status impacted upon the dental care he received because due to his haemophilia, he received all of his dental care at the GRO-B Hospital in Oxford.

110. I was offered bereavement counselling by both the Oxford Haemophilia and Thrombosis Centre at the Churchill, and from the McFarlane Trust. However, I did not take this up.

111. I do not know whether H was offered counselling or psychological support as a result of his HIV and/or HBV diagnosis. He may have been offered counselling, but I do not believe that he would have accepted their offer. His attitude was very much *"what's the point, they can't take the HIV and Hepatitis away from me*?"

Section 7. Financial Assistance

112. H was already aware of the Macfarlane Trust when I met him in 1988. I assume that he would have been told about the Trust by the Oxford Haemophilia Centre at the Churchill. I think that the financial assistance from the Macfarlane Trust came about when he took early retirement. He used to receive the winter fuel allowance from them back when he was working.

113. As a result of his HIV infection, H received a lump sum payment of £30,000 from the Macfarlane Trust.

114. The Macfarlane Trust helped us a lot. One of their staff members named Roz was brilliant. H was provided with a monthly payment which had increased quite a bit over time and his last payments were around £1060 a month. I continued to receive this monthly payment up until around six months after his death. They paid £3,000 towards H s funeral costs, and I received carers allowance for around one or two months after his death. His funeral cost over £4,000.

115. After H s death, the Macfarlane Trust paid £350 a month towards the girls. I was also able to claim expenses for any school trips and help towards their school uniform. In around 2012, any financial assistance received from the Macfarlane Trust stopped. This made me angry as the Macfarlane Trust was set up to help those infected and their children. It was the principle of what the Macfarlane Trust was set up for and its failure to meet their core aim annoyed me. It was not about the money.

116. I made a claim against the Macfarlane Trust, but as I had met my current husband GRO-B at the time, they said I was not entitled to anything. In 2013, they then realised that I should have still been in receipt of payments for our girls and they made a back-dated payment.

117. Around three to four years after H s death, the Skipton Fund contacted me. They had stated that as a bereaved spouse, I was owed a lump sum payment of £10,000. I asked the telephone operator what the money was for, to which he had told me that it was attributable to H s HBV infection. I replied something along the lines of, "*So his life was worth £40,000?*" In response, the telephone operator had said that he was sorry and he didn't really know what to say. He wasn't being ignorant he just didn't know how to react. I asked him what he was sorry for? It was not about the money. It was about receiving recognition that H and others out there were not just a number whose lives were equal to such a

small sum of financial assistance. They were people who had lives, parents, families, and children.

118. In around 2017 I was contacted by the English Infected Blood Support Scheme ("EIBSS"). I was told that I was owed financial assistance for my daughters, but within a short period of time the money stopped, started again and then stopped. I grew too tired to argue, so I did not both contacting the EIBSS again.

119. Recently, on 1 December 2021 I received a lump sum payment of £89,000 into my bank account which I believe to have been from EIBSS. I phoned them to ask for what it was for. I was told that it was a back payment for money I was owed. I asked if she was sure, because previously money had started, stopped and started again.

Section 8. Other Issues

120. With regards to the Contaminated blood scandal ("CBS"), it has destroyed so many lives. I believe that the Government knew that the blood and blood product they sourced from the United stated was infected, or, that it had the potential to be infected. They knew that the blood was being donated by people who were at a heighted risk of having a blood borne infection, such as drug addicts and prostitutes. Yet, they still decided to cut corners to save money and source blood from areas where blood was readily available, despite the risk.

121. H had always said that he did not trust the Government. If they knew that there was even a slight chance that the treatment which was going to be given to patients could be unsafe, then they should not have authorised this treatment to be used in the medical setting. This decision destroyed not only the patient themselves, but everyone else around them. There is a ripple effect which affects generations and generations.

122. After losing H there are certain periods of the year where I really struggle. I cannot bear Christmas time, the anniversary of H s birthday and his death. H

loved Christmas but I now hate it as I miss him so much and I am likely to be on anti-depressants all my life as a result, although the dose has reduced over time.

123. With all the haemophiliacs receiving treatment under the National Health Service ("NHS") like H, they did not have a voice or a choice. It is all about choice. They should have been told about any risk, so that they could make an informed decision on whether to provide consent to receiving treatment with blood product.

124. H had a personal connection with two other haemophiliacs, with whom he attended GRO-B School, GRO-B, GRO-B which was a special needs school. He became friends with a pair of twins who were also haemophiliacs, and who had become infected with HIV. One of the twins had subsequently died as a result of their HIV infection in his early twenties.

125. When I received a telephone call from a member of the Infected Blood Inquiry Team, at first, I was very hesitant to engage. However, GRO-B stated something along the lines of, *"You need to put it out there just how much it destroyed H Nothing will bring him back, but it destroyed his life, and it destroyed your life when you were together."* I agreed. My daughters also wanted me to give a statement to the Inquiry.

126. Providing a witness statement to the Infected Blood Inquiry has allowed me to give H a voice. I often think why was he dealt a 'bad hand'? He was only fifteen years old when he was infected with HIV. He was the same age that my youngest daughter is on the date of drafting my witness statement. Could you imagine being a mother, and being told that your child has a life-changing infection? It is the same as being told that they have cancer, but without the stigma attached to HIV.

127. Whilst his death was over eleven years ago, it feels as though it happened yesterday. That day when H told me about his HIV, I could have walked away, but I loved him. If I could have him back, I would. I would have him back as long as he did not suffer as a result of the stigma, drugs, and the physical and mental

effects. On the inside it broke him. I would not wish the suffering he went through on my worst enemy. He used to say *"yes, I have been dealt a bad hand, but I have the love of my life and my two daughters.*"

128. To date, I get so angry. If it was not for the HIV, he could potentially still be here today. He missed out on his life with our daughters. He did not get to walk them down the aisle, or watch them grow up. Instead, he had a life sentence around his neck.

129. I would like the Infected Blood Inquiry to recommend some sort of education surrounding the stigma associated with HIV. To date, the stigma is still prevalent, and this is so wrong.

130. Whilst a recommendation of compensation would help my girls in the future, no amount of compensation is ever going to bring my H back. No apology, no money or anything can change that. In a way, compensation suggests that he was just a number with no voice. No, he was not a number, he was my husband and a person who lost his life at such a young age through no fault of his own. He was one in a million.

Statement of Truth

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

Signed GRO-B

Dated 17.2.2022.