Witness Name: GRO-B
Statement No: WITN0128001
Exhibits: None
Dated: 15 November 2018

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 18 October 2018.

I, GRO-B, will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1965 and my address is known to the Inquiry. I am a self-employed consultant. I am married and I have one son. I am a mild Haemophiliac. **I wish for my identity to remain anonymous.**

2. I intend to speak about my deceased brother who was infected with Human Immunodeficiency Virus ("HIV") and Hepatitis, which he contracted as a result of being given contaminated blood products to treat his Haemophilia disorder.

3. In particular, I will talk about the nature of my brother's illness, how the illness affected him, the treatment that he received and the truly devastating impact that it had on my life and the rest of our family.

4. I confirm that I do not have legal representation and I am happy for the Inquiry team to take my witness statement.

5. **NOT RELEVANT**

6. My brother was born on GRO-B 1961. He was diagnosed with severe Haemophilia A that year. He was given contaminated blood products (Cryoprecipitate and Factor VIII) to treat his Haemophilia; these products infected him with HIV and Hepatitis sometime during the 1970's and/or 1980's. He died of Acquired Immune Deficiency Syndrome "(AIDS") on GRO-B GRO-B 1991, aged thirty.

Section 2. How Affected

7. My brother was diagnosed with severe Haemophilia A when he was nine months old. He was tested after he lost a tooth and it failed to stop bleeding.

8. Following my brother's diagnosis, myself, my other brother and sister also had to be tested. They tested me when I was born, when I was a teenager and again when I was an adult. However, they didn't tell me that I was a carrier for Haemophilia until I was 19 years old and even then I had to ask if I had it. They really should have told me sooner, I was having horrendous periods and it could have been dangerous. I now carry a medical card to explain my condition. I believe that because I am only a carrier for haemophilia (only a third of which present symptoms that are similar to mild haemophilia) I was not taken seriously.

9. We always knew that my brother was a Haemophiliac and we were told that we had to take care of him. I was very close with my two brothers and my sister. I think this was accentuated by the fact that my mother and father split up, which was unusual at the time.

10. My brother's Haemophilia became a big part of our childhood, as did the Haemophilia Centre Ward at the Royal Victoria Infirmary ("RVI") in Newcastle. My brother's primary contact at the RVI was the Senior Doctor of Haemophilia, Doctor Peter Jones. I remember a particularly bad time when my brother was in the hospital for four months continuously, he even had to spend Christmas in there.

11. When my brother was younger he was treated with Cryoprecipitate, he wasn't given Factor VIII until he was a teenager. He never had transfusions, it was always Factor VIII, and this was pooled from hundreds of people's blood. I remember my brother said that he was never fully informed of any risks of contamination and that they should have given him the choice of using Cryoprecipitate, which was less risky.

12. Doctor Jones and the nursing sister informed my brother that he was infected in about 1987 in a face-to-face appointment at the RVI. My brother's wife had recently given birth to their first child and she was also present. Doctor Jones told him that he was infected with HIV and it had already converted to AIDS, he then delivered even worse news that he had infected his wife. I think that my brother was also infected with a form of Hepatitis. Their son was later tested and fortunately found to be clear of both the viruses.

13. I do not feel that my brother was given adequate information about his condition at the time. The healthcare professionals did not pass on information about his infected status to him at an early enough stage, this resulted in him passing the virus on to his wife.

14. I think that the way in which my brother and his wife were delivered the news of both of their infections was deeply callous and inhumane. It did not meet the professional obligations that it should have. They were not treating patients with respect or dignity. The whole way through this episode my brother and his wife were treated appallingly.

~~15.~~ Not only did my brother have AIDS and Hepatitis, but he also had Haemophilia. There was a lack of understanding by some in the medical profession of the double burden he carried.

16. I was living in GRO-B and my brother was living up near to GRO-B when he broke the news of his infection to me. I was absolutely devastated.

17. My brother's condition deteriorated rapidly and he passed away at the RVI on GRO-B 1991. My sister was worried about me so she took care of the funeral arrangements. We were all told to say goodbye to my brother quickly. After he died his body had to be put in a body bag and cremated.

18. In 1999 I gave birth to my son. Severe Haemophilia runs true in the family (unless you are a female) and my son is a severe Haemophiliac. He has to take blood products every other day. He is only 19 and is currently studying at university, but at some stage may decide to be tested for HIV and Hepatitis; touch wood his tests will be negative. But I still worry to the day about my son's blood products and if they are clear. I do not think some medical staff understand the fear that still permeates families who have been so severely impacted by this trauma.

Section 3. Other Infections

19. To the best of my knowledge my brother did not contract any infections other than the HIV and Hepatitis as a result of being given infected blood products.

Section 4. Consent

20. I believe that the healthcare professionals involved in my brother's care knowingly tested him without his consent and without giving him adequate information.

21. I have been asked if my brother was ever tested or treated for the purpose of medical research and to the best of my knowledge he was not.

Section 5. Impact

22. The physical effects of the AIDS on my brother were profound and devastating. In the few years from when he was told about his infection until his death he experienced a massive decline in his condition. He was bloated because of all of the drugs, he was in a wheelchair, he had a fungal infection in his lungs, he lost a lot of weight and was emaciated towards the end.

23. My brother's infection also had a severe psychological impact on him, he knew that he was dying and he was deeply worried about his wife. My brother died thinking that his wife may die of the same thing.

24. My brother was on AZT to treat the AIDS and he had severe reactions to it. He was on a cocktail of medications; I don't know what they all were. The centre at the RVI tried to support him. I believe that they may have had more Haemophiliacs than any other part of the country and my brother knew one family where three Haemophiliacs died.

25. I have been asked whether my brother faced any difficulties or obstacles in accessing treatment and I am not aware that he did. Nor am I aware of any other treatments that ought to have been made available to him. I do think that my brother's infected status impacted upon other medical or dental treatment, making it more problematic and humiliating to access treatments. For example, when undergoing dental treatment, staff are fully

gowned to protect themselves. Whilst this precaution is understandable, I remember both my brother and sister-in-law commenting that it makes you feel like a leper.

26. My brother's AIDS had a huge and devastating impact on his family. His son was only four when he died. His wife was left to care for him as well as dealing with her own infection with HIV. When his wife found out that she was infected she couldn't get out of bed for a week. Then as a young woman she had to watch her husband die of something that she thought she would also die from and deal with the horrendous stigma surrounding the condition. It is not an exaggeration to say that "they feared for their lives." They were terrified that the news of their status would leak out and they would suffer violence and rejection if that were the case. This was an enormous psychological burden to bear, as well as dealing with the medical issues. How she is still here standing today I don't know. It completely affected her life.

27. After my brother's death his widow got involved with **GRO-B** she later married him. **GRO-C** **GRO-C** **GRO-C** He would blackmail her by saying "if you leave me I will tell everyone about your HIV status." **GRO-C** **GRO-C** If my brother's widow had been offered proper support I do not think that relationship would have ever happened.

28. Our family tried not to let my brother's infection affect our relationship with him, but it did make us think that we had to be extra careful because there was the worry of contamination. Although you cannot get HIV from normal interaction it made everyone paranoid and you could not help but be affected by this.

29. We are an extremely close family so it devastated us all. It was especially horrible for my other brother as he had just finished his **GRO-B** training and

there was so much news about AIDS everywhere. He completed his training, being bombarded with news about this new, dreadful condition, knowing his own brother was affected. It was a dreadful and painful dilemma for him.

30. As I mentioned previously, my parents were divorced. My Mum broke down and it accentuated her drinking problems. She eventually managed to overcome her alcoholism, but has now passed away. My Dad was estranged, but he got in touch with my brother before he died. We have all been through terrible pain and anguish.

31. My brother's infection and subsequent death left me feeling absolutely devastated. I was 21 when I found out that he had AIDS and I was 25 when he died. It was the most excruciating experience that I have ever gone through. I knew my brother was dying, but I could not tell a single soul what was actually happening. I had to live my life "as normal," fielding questions from friends and colleagues about my brother, who they knew had haemophilia, and whether he was affected. I had to lie. I had to make up stories to explain why I was visiting home more than before. I had to pretend that all was normal, while inside my heart was breaking. It felt as if my whole life was based on deceit and subterfuge. When your relative is dying, you need help and support. You need to be able to talk about your grief and rage and pain. All of this was denied to our family. The only people I could speak to honestly were my brother and sister and there comes a point when you don't want to do this anymore because they too are suffering so much. So you are truly alone - isolated, stuck in some hideous cage of pain with no key to get out. You cannot live a healthy, integrated life, when you are living a lie and can't talk about your grief. To watch someone die under such cruel circumstances and literally have no-one you can share this with, is a unique kind of mental torture. One day, I woke up and I felt I couldn't go on an longer. I remember being on my own in my third floor flat, sitting on the window sill and thinking "I'm going to jump". The pain and injustice of it all was too much.

The only thing that stopped me was knowing that this would be too cruel for my mother and family.

32. I still cry to this day when I think of what's happened and how much I miss him.

33. What happened to my brother caused me to have a series of relationships that were wrong for me, because I was so needy. Without doubt, it changed the course of my life. The year before his death I went with my friends to Trafalgar Square for New Year's Eve and a police officer found me alone, on the pavement, sobbing my heart out. All I could think about was how that would be my last normal New Year's because soon by brother would be dead. I saw him as much as I could before he died.

34. I felt impotent and a deep anger which spilled over into all kinds of stupid things that I did. I fell out with friends and family, I would drive really fast and I didn't care if I died. I really struggled to hold it together.

35. I had to seek counselling for 18 months at my own expense. My counsellor put the situation into perspective by telling me that I knew two infected people, there was a lack of justice and I couldn't tell anyone the truth; I was living a lie. I later became a trained counsellor, although I don't practice so I know that if you internalise your grief and don't vocalise it, you cannot cope.

36. My brother asked us to give our word that we wouldn't say anything about how he died. But I was honest with my son; I had to tell him in case he found out some other way. Understandably my son was really upset. How would you feel if at 19 you found out that your uncle died of a complication of your disease? He is now having counselling and the counsellor has told him that being upset and angry is completely understandable.

37. Our family weren't able to tell anyone what was wrong with my brother due to the stigma that surrounded AIDS. It was like the black plague. We had to pretend that everything was okay. Someone with cancer can tell

people why they are sick and get sympathy, if we told anyone we would have been harassed.

38. Freddy Mercury was in the media a lot at the time and people were talking about AIDS. What people were saying applied to my brother, but I couldn't say anything. We had to tell people that he passed away due to a brain haemorrhage, which was partially true, but it was the AIDS that caused it. Even at his funeral I'm sure that my brother's friends' thought, I know what he really died of, but no one talked about it.

39. My brother was GRO-B and his illness definitely impacted his work, especially as his condition deteriorated. The money worries probably angered him the most. He was involved in litigation and I believe he was given the option of £60,000 because his wife was also infected, but he had to sign a gagging order. He felt that he had no choice but to sign this, as he needed to leave some money for his wife and child. However, this was deeply unfair, he shouldn't have been gagged if further information came to light. They were effectively told that they couldn't do anything and I'm not sure that's legal.

40. From the time that I found out about my brother's illness it was like I was living in a horrendous horror story. Not long after I found out I collapsed at work. The pain was excruciating and I wasn't sure that I could bear it. I continued working, but I was overcome with grief. I was a young woman trying to start her life and I really struggled to deal with this ongoing horror.

Section 6. Treatment/Care/Support

41. I mentioned previously I am not aware that my brother faced any difficulties or obstacles in obtaining treatment for his AIDS.

42. My brother was offered GRO-B support in the form of a GRO-B GRO-B but he was very unprofessional and hit on my sister-in-law.

43. The thing that happened to my brother was the biggest earthquake that I have ever had to deal with. No counselling was ever offered to me and as I mentioned previously I had to seek my own counselling at my own expense. There was a complete lack of regard or understanding for the wider family. Especially for me, a young woman who is a carrier for Haemophilia, they should have thought how can we help her, but no thought was there.

44. If my brother's widow had been provided with adequate psychological support **GRO-C**

GRO-C

Section 7. Financial Assistance

45. I have been asked how my brother found out about the Trusts and Funds that provide financial assistance, and which one he applied to; I do not know which scheme he was under. But I think that he received £20,000 for being an infected Haemophiliac and £20,000 for his partner being infected.

Section 8. Other Issues

46. I am a member of the Haemophilia Society, but I have never been involved in any litigation, other Inquires or campaigning.

47. I also have a few other concerns that I would like to bring to light:

Treatment of Haemophilia

48. In 1999 when my son was born at the John Radcliffe Hospital in Oxford, I witnessed how utterly callous medical professionals can be towards Haemophilia. I knew that there was a fifty per cent chance that my son

would have Haemophilia. After his birth, my placenta was tested. I could tell by the look on the obstetricians face that he had it; he said to me "Why are you crying? Look on the bright side, he will never die of a stroke." My son was born at 3:00 am; I was given the upsetting news and was discharged at 15:00 hours.

49. Three weeks after my son's birth the nurse came to see me. She said I shouldn't be telling you this, (but I think she wanted to get one over on the haematologist) but after my son's Haemophilia diagnosis Doctor Paul Giangrande went back to the nurses and said, "Good, that's another one, we will get more funding." This showed me that Haemophiliacs were only seen by some as a unit to give them more money. Other clinicians who cared for my son were caring and professional.

50. I encountered another issue with the treatment of Haemophilia when my son was about six years old. He developed inhibitors, which is where your body rejects treatment, this is very serious for children with Haemophilia. To treat this they bombard the system with Factor VIII to overcome the immune response, it is very expensive and the patient must have it twice daily. The doctor wanted to give my son porcine Factor VIII, but I fought tooth and nail to keep him on his current treatment.

51. My son had PUP status (Previously Untreated Patient) so he was always at the top of the queue for treatment. However, my brother told me that if he had the porcine factor he would lose that status; I conducted my own research that confirmed this. After I discovered this I sat down with the consultant and said if there is no financial reason for putting my son on this product then I will consider it. What angered me was that the healthcare professionals weren't honest with me, they didn't tell me that about loosing the PUP status and they cared about saving money.

52. Doctor Jones made some inappropriate comments about my sister and I; he said that we were the blonde equivalent of the Nolan sisters. He also made creepy comments to my sister-in-law about how attractive she was

and how lucky my brother was to have found someone so gorgeous. In those days he was perceived as a god and no one would question him. Consequently, he and my brother had a fractious relationship.

53. Another instance where a doctor failed to obtain consent occurred in relation to my son. I went to see Doctor Paul Giangrande (who was the Head of the Haemophilia Department at the John Radcliffe Hospital in Oxford) for a consultation with my son concerning GRO-B It is very unusual for a child with Haemophilia to have GRO-B

GRO-B

Close relationship between the drug companies and doctors

54. In about 2008 I moved to my current village. I had to have a minor gynaecology procedure and needed haematology cover for the DDAVP clotting agent. I went to see a haematologist called Doctor Parapia at a private clinic in Yorkshire. During my first appointment we got chatting about my family background, I told him about my brother passing away and that my other brother worked locally GRO-B He said that he didn't come across many people with Haemophilia and that he liked me because I was brighter than his usual NHS patients.

55. GRO-B

56. I told him that I was still devastated by what happened to my brother and I asked him how many people he knew that were impacted. He said that he had some of these people under his care. We talked about the tragedy and I opened up about the impact it had on me. Doctor Parapia GRO-B

GRO-B said that he had been troubled by the fact that he knew there was too much of a cosy relationship between the drug companies and some of the doctors, and that he had information that proved there was collusion between them. I asked what he knew and if he was one of those doctors, but he wouldn't answer, he shut me down and changed the subject. I think he realised he had said too much, GRO-B GRO-B

57. I left shortly after that, I was upset, but I didn't show it. Internally I was raging and in complete turmoil. When I got home I thought about it all and I couldn't believe what I had just heard. GRO-B

GRO-B

58. Doctor Parapia clearly has information or knowledge about the very close incestuous relationship that existed between the drug companies and doctors and I think that he should be questioned on it.

59. GRO-B

The infected blood scandal

60. I think that the infected blood scandal is the worst scandal ever, even worse than Hillsborough. Successive governments have refused to look into it and there has been a total lack of support. Ken Clarke said that only Haemophiliacs are affected. Sometimes it just needs someone to say that they are sorry, be honest and properly compensate the patients affected.

61. I don't understand why these drug companies aren't culpable. From an evidential point of view they knew that they were buying blood from these undesirable people, like drug addicts. They don't deny that these products were infected, so why aren't they guilty of corporate manslaughter?

Exploitation

62. There is absolutely no doubt in my mind that the medical professionals were informed of the growing risks but still used the products, the arrogance of the medical profession was appalling. I believe that infected people have been exploited because they cannot speak publicly about what has happened due to the stigma. My brother's widow has been blocked from getting hold of his information. She feels dependant on them because she is still getting HIV care from the NHS.

The Inquiry

63. This Inquiry is the first time that the unvarnished truth has been told. The video at the preliminary hearings was so moving and appropriate. Putting the messages in the blood bottles was a very powerful gesture; it reminded me of going to the hospital with my son and my late brother. I just hope that it gets to the truth.

64. After the Inquiry is over I think that there should be an event, much like the preliminary hearings, so that everyone that has been involved can meet up and achieve some measure of closure. It should publicly name and shame the offenders – particularly those who have sought to suppress the truth. And finally, and most importantly, this event should acknowledge the tremendous strength, fortitude and bravery families and campaigners have shown in their quest for justice and truth and be a commemoration of those who have died.

Statement of Truth

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

Signed **GRO-B**

Dated 20/11/18