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Witness Name: GRO-B

Statement No: WITN268701

Exhibits: WITN268702-05

Dated: 16 April 2019

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 1 February 2019.

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

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1955 and my address is known to the inquiry. My husband GRO-B and I were married GRO-C but we had been together for many years before then. We had GRO-C children together and I had my first child when I was sixteen years old. My son GRO-C: s was my GRO-C child. The eldest is now GRO-C years old and my youngest GRO-C. My husband is now retired. He worked as a sheet metal worker for 24 years and was also a bus driver. I have GRO-C sons diagnosed with haemophilia. My GRO-C daughter is not a haemophiliac carrier.

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2. In my statement I intend to speak about the impact of [S] infection with HIV and Hepatitis C (HCV) on him, our family and on our lives together. I want to make this statement for [S] and I am willing to give oral evidence.

Section 2. How Affected

3. My husband was a sheet metal worker. When his company moved to [GRO-C] he had to work away a lot so I was at home with the children.
4. My late son [S] was my fourth child and was born on [GRO-C] 1978 with severe haemophilia. I intend to speak about his infection with the HIV virus and the Hepatitis C virus (HCV) which he was infected with from contaminated blood given to him in the form of Factor VIII products to treat his haemophilia. I will go on to describe in particular, the nature of his illness, how the illness affected him and how it affected myself and my family, the treatment [S] received and the impact it had on him and our lives together until he passed away on the [GRO-C] 1994 when he was just 15 years old.
5. [S] was infected with HIV and Hepatitis C (HCV). We found out about the HIV infection during a visit to Charing Cross hospital for [S] loose tooth. We never received anything in writing. We were told about the Hepatitis C infection after [S] had died in connection to the Skipton Fund.
6. When [S] was born he was tested for haemophilia straight away and it was confirmed as severe. I was always aware of his condition and I used to wrap him up in 'cotton wool' so to speak, to protect him from bruising. He didn't walk until he was 2 years which was my fault really because I was frightened he would get hurt. Whilst hospitalised for treatment, he learnt to walk. [S] was a very easy child. He weighed 8lbs14oz at birth and was a lovely chubby boy who needed no

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treatment for haemophilia for the first 18 months of his life. However, in 1980 he started treatment to manage his condition.

7. To give some background, [S] older brother who was my [GRO-C] born was around 18 months old before he was diagnosed with severe haemophilia. He bruised easily and when he started moving around, he bruised like I'd never known. When he was 10 months old he hit his head on the side of his cot and it swelled badly. I took him to the GP who then referred us to St Charles hospital at Ladbroke Grove where they gave him transfusions but the blood kept disappearing and they didn't know why so they transferred him to Middlesex hospital. The police came and collected me in the middle of the night to take me there. They were going to drain his skull but luckily they decided not to operate.
8. From day one they thought that I had caused his bruising or that my [GRO-C] eldest were hurting him, they were only [GRO-C] years old at the time. Medical students would be taken to see him and they were told that he was a battered child. After he was sent home following his head injury, I used to keep him in a buggy, as I was scared of him hurting himself. One day he bit his tongue and it took 3 weeks to heal and smelt like a slab of meat. The doctor just kept swabbing it and sent us to St Charles's hospital because it wouldn't heal. They used to be quite horrible to me at St Charles's, particularly one doctor who accused me of battering my son. They sent a social worker to see us each week and said they would take the children away if we didn't let them in.
9. Eventually, one doctor from St.Charles hospital suspected haemophilia due to us having to take him there after he woke up with swelling under his arm. The doctor informed me that he shouldn't be injected by the groin or the neck (as they normally do). Later that evening during visiting hours, I had noticed one of the injection sites in his groin was bleeding, whilst changing his nappy. When I mentioned his groin to one of the doctors at St Charles', one nurse said, "Come on what's happened this time, did he fall over a football?" We were again

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wrongly labelled as child batterers. The same doctor who we saw later on in the day informed them that actually he had just been diagnosed with Haemophilia.

10. We had to go to Great Ormond Street hospital to have the diagnosis confirmed. When we were sent to Great Ormond Street we were told not to say anything more and they sent one of the nurses in the ambulance to prevent me saying anything. Great Ormond Street asked the nurse why they hadn't noticed his condition and asked what syringes they had been using.
11. It took 11 months for his final diagnosis of severe haemophilia. We had never heard of haemophilia before and there was nothing in my family history. I am one of 7 girls and 3 boys and no one else in my family was affected. By then I was pregnant with [S] so they carried out tests for haemophilia. I was pregnant with [S] in late 1977. I was six months pregnant with [S] when I was told that a test had revealed that my [GRO-C]son suffered from a form of haemophilia. [S] was then tested at birth.
12. At the time we lived in a flat on the 10th floor with no working lift so the council later rehoused us to be nearer Charing Cross hospital. I noticed that the social worker kept coming after my son's haemophilia diagnosis and we moved so I wanted to know why? I was told he was not supposed to be visiting and he got told off and the visits stopped around 1979.
13. [S] needed his first treatment after we had been travelling on a coach to Burnley to visit my sister. I held him on my lap and something must have happened maybe in the position he was sitting, as he couldn't move his arm. I took him to Victoria hospital in Burnley and told him that he had haemophilia so they called Charing Cross hospital for advice. They gave him cryoprecipitate via an injection in his arm and kept him in overnight. This was the first time [S] had needed treatment for his haemophilia.

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14. Charing Cross hospital kept beds for haemophiliac children, . We seemed to be going to Charing Cross a lot with my boys. They didn't have a haemophilia ward at Charing Cross so you would have to wait until they sent the Cryoprecipitate treatment down to the ward. The Cryoprecipitate would only last 2 hours before it was no good to use.
15. used to be treated with Cryoprecipitate. medication was then changed to Factor VIII. In 1983 Factor VIII came in and they started training me to give it to by injection around this time. I was first trained on an Orange, then, one brave doctor at Charing Cross hospital let me do it to him. If he wanted a blood test done he would let me put it into the tubes and that's how I first learnt.
16. had been going to hospital on a regular basis. When this new drug came in I was told it would be easier for us as they wouldn't need to come into hospital so often as they had to with cryoprecipitate treatment. So as soon as they had a bleed I could give the treatment, which we kept in our fridge.
17. There was no warning around Factor VIII. It seemed like a brilliant thing because you could give it to them straight away so there were no bad bleeds. We were not told where Factor VIII came from. Cryoprecipitate was fresh and didn't last long so Factor VIII was better because it was kept in the fridge and could be administered when needed. It was easier because we didn't have to run to the hospital and when used to have the Cryoprecipitate it was a bit of a struggle because he didn't like it when he was about 4 or 5 because so we had to roll him up in a sheet and lots of us hold him, which made it so much worse. was a very nice child but he didn't like that treatment.
18. In 1984-85 when was 7 years old, he had a loose milk tooth, which was causing him problems because it wouldn't come out due to a haematoma swelling caused by his haemophilia. One of the doctors,

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(I cannot recall her name), from the haematology department (there was no haemophilia unit at Charing Cross hospital then) said she would call the dentist to take a look. So I took [S] to Charing Cross Hospital to see the specialist dentist there.

19. The dentist kept trying to give reasons not to come down and said the tooth would come out eventually. Where it was so wobbly he couldn't eat properly and because the gum was so swollen it wouldn't allow the tooth to come out.
20. I was frightened and concerned because the dentist came in wearing something that I can only describe as 'space suit' she looked like she was going into outer space. She came covered up in a mask and a suit and it frightened me because I didn't know what was going on. When I tried to show her his tooth I got the impression she backed away and she wouldn't go near [S] or look into his mouth. I felt scared when she did this and I knew something was not right. [S] was a little 7 year old boy, he must have wondered what was going on, seeing her dressed like that. The doctor told the dentist to take the tooth out so she took [S] tooth out accompanied by a nurse and it came out in a matter of seconds.
21. I asked the doctor what was going on and she took me into a room and told me that both my boys had been tested positive for HIV. I was given a blue plastic bottle and plastic gloves. She just said that in future, when using the Factor VIII that I should use the bottle and the gloves and put any needles in the bottle. She told me to wear gloves. I didn't really know what this meant.
22. I did not even know what HIV was. I didn't know what the diagnosis meant and how it might affect [S] in the long term. I told the nurse I had a baby at home, my daughter was [GRO-C] years old at the time and I asked her for advice on what I should do, but her only response was that she didn't know. She left me to go home on my own.

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23. I wasn't aware that they were being tested. I had no knowledge of them testing my boys before then and I didn't know who had authorised the tests. She said the tests had come back positive. They didn't tell us when or why they were done. I asked her what she meant. When the doctor was telling me what the problem was I was thinking about all my other children and I asked the doctor what it meant and what I should do. Her response was that she didn't know.
24. I was not given any advice by the hospital at all and I was not given any other advice about what I should do next. I was never given any leaflets and I never received anything in writing from the hospital to confirm the HIV diagnosis. I do not feel that adequate information was ever given to me about HIV and no attempt was made to help me to understand and manage the infection. I was never given any advice about risk to my family. I was given no advice whatsoever other than the bottle and using gloves when injecting Factor VIII.
25. After I had been told that [S] was HIV positive I didn't know what to do. I ran to my sister who lives around the corner because I had to speak to someone. She was calming me down. I phoned GRO-B and he came straight home. My older sister reacted with shock when I first went to her to tell her. But at that point we didn't understand what was meant by it.
26. A few days later my GP showed up at my front door with a lady (I am not sure who she was). He said that they had been told by Charing Cross Hospital that they had to inform [S] school that [S] had contracted HIV. I didn't understand why they needed to inform the school but I never noticed the school treat either myself, or [S] any differently after this, the school never said anything to me about it. I didn't notice any change by my GP in their treatment of us either but we generally always went to the hospital because of the specialist haemophilia department there if there was a problem.

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27. Even though they told us about the HIV we didn't realise how bad it was. In 1984-85 a lot of horrible things were going on in the news and HIV was reported as a gay disease. A week later my sister rang me about a newspaper article her neighbour had had seen, (I think in the Daily Star) about 3 haemophiliac children with AIDS who were dying in Charing Cross hospital. I knew of only 3 haemophiliac children in Charing Cross hospital, my 2 sons and another boy. I told the doctor at Charing Cross about the newspaper article and she said it wasn't AIDS it was HIV and when they found out who had told the press that person would be in trouble. I was never told of the outcome of this or who had informed the papers. I would think a copy of this article would still be available.

28. Also, a man who ^{GRO-B} worked with in GRO-C told him that his father had been at Charing Cross hospital and had heard about the 3 boys and that 2 of them were brothers with AIDS. ^{GRO-B} said that he must have been talking about our 2 boys and the other boy at Charing Cross. We hadn't put AIDS and HIV together until then. My husband and I didn't really associate HIV with AIDS, so it came as a shock. We thought what is it? It was a pretty traumatic time.

29. Although the hospital was telling me these things I didn't seriously feel anything was going to happen. There were things in the papers about AIDS but I didn't think it had anything to do with haemophilia. I thought it was to do with gay people. S HIV infection developed into AIDS but we didn't realise.

30. S continued to attend his usual check ups. S was transferred to St Thomas Hospital in 1986 as the hospital had a specialist unit for haemophilia and it was felt that he could be better looked after there. We saw Dr O'Doherty and Chris Harrington. Dr Savage was the head of the Haemophilia Unit at the time. Dr O'Doherty was the doctor at St Thomas for AIDS along with a nurse called Chris Harrington and Dr O'Doherty was the one who introduced S to AZT.

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31. The hospital told me that they wanted me to tell [S] about his HIV but he was so young and I didn't feel it would be any use to tell him. I didn't feel he should know. I could not imagine how little boys were told they were infected. I was never going to tell [S] at the age of 7 or 8. I was not given any support or guidance on how to tell him by the hospital. The hospital kept telling us from day one that we should tell them but I didn't want to and didn't see why they should be told. When they got to 11 and 12 the hospital said we should tell them. I think they were thinking more about the boys getting into their teenage years and meeting girls. I didn't want to put it on them.

32. Eventually we told [S] he was infected with HIV when he was older and in his teens when he was about 13 or 14. We took [S] and his brother into our bedroom and told them together. They just sat there. They didn't say much about it. I didn't make it sound as bad as it was they went quiet and went on their way. I don't think they took it in. [S] said that he thought there was always something wrong as I didn't treat him the same as the others and made him wear a hat and scarf. I didn't think he really understood what I was saying. I was never offered any help, support or guidance about how to tell him.

33. I told them to be careful around cutting themselves. I explained that was why I had to wear gloves for that reason. If anyone got a cold around them I told them I didn't want them catching a cold and things like that. That is how we told them.

34. [S] brother didn't want anyone to know he had haemophilia and HIV. Even now he doesn't talk about it. He has his problems but he has only just started having medicine for the HIV a couple of years ago.

35. Sadly, [S] died on the [GRO-C] 1994. His death certificate recorded perforated ulcer. We were told that we could see him in the Chapel of Rest but after we had visited him they told us that we didn't

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need to go to the hospital anymore. It was almost like once he died he was forgotten about.

36. It felt like he was just being air brushed away and the hospital treated our situation like it was over with and they said to us that there was nothing to worry about anymore. This is why I want to tell [S] story. I don't feel ashamed about what happened and I am more than willing to give oral evidence. I am making this statement for [S]

37. After [S] died in St Thomas's hospital, a member of staff took him to the Chapel of Rest and told us to come back on the Monday. We had to get someone to take us down and we met Dr [GRO-D] at the door and he told us that we didn't have to go up there all the time anymore. This always stuck in my mind it was like he's gone now and they were telling us we didn't have to worry. [S] never got the chance to grow up and it shouldn't have happened.

38. Surprisingly we didn't have any problems with the undertakers in connection with the HIV. The hospital recommended them. The funeral director was a Priest and had been an old head teacher at my children's school. He was fantastic and very helpful, he got us through it really, he let us go and see [S] quite a lot in the chapel of rest before the funeral. He treated us with respect and dignity.

39. It was only later after [S] had died that I discovered that [S] had been keeping a diary of his private thoughts. [S] never spoke to me about his condition, but after he died I found out that he had been writing it all down in diaries. I have read these, amongst many things he speaks about his treatment, about his hopes and ambitions. Towards the end, how bad he was feeling and the difficulties he was experiencing, some of which I had no idea. This really upset me. It was clear that he was keeping everything from everybody. [S] covered his diary and an exercise book entitled "My Feelings and My life" with pictures and drawings.

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40. The content is very private and my husband cannot bring himself to read them, consequently I am only producing the covers of the diaries to the Inquiry. These are: **WITN268702 - WITN268703 - WITN268704**
41. In 2011 when the Skipton Fund contacted me, I was asked whether [S] had been infected with Hepatitis C. I contacted St Thomas Hospital who checked their records and they told me that [S] had also been infected with Hepatitis C. We had not been aware or informed of this whilst he was alive.
42. Just after [S] died one of the nurses said that the problem for [S] was that it had happened to him too soon. [S] was about 12 when they gave him AZT because they said there was something wrong with his white blood cells. They gave it to him and he went down hill from then. His brother wasn't put on AZT and survives to this day.

Section 3. Other Infections

43. As result of his HIV infection, [S] suffered from terrible ulcers in his mouth, which spread to his stomach, thrush of his mouth and cold sores. He also contracted TB and we were told that he had a form of cancer attributed to AIDS. He was also anaemic. These further illnesses surfaced in the last stages of his life and made him very ill.
44. As I mentioned earlier, after [S] died we found out via the Skipton Fund, who had contacted us, that [S] had also been infected with Hepatitis C. We were never told about this diagnosis whilst he was alive and we were never told that he was tested for it.

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Section 4. Consent

45. I never gave my consent for [S] to be tested for HIV or HCV and I didn't know they were going to test [S] for HIV. I only found out that he had been infected from his dentist at Charing Cross hospital when he needed a tooth extracted when I asked why the dentist was gowned up in a head to toe suit.
46. I found out after [S] had died that he had been tested for HCV whilst he was at St Thomas's without my knowledge or consent and this was years after he had passed away.
47. I am not aware of any liver scans that [S] had in relation to HCV. He used to fall asleep when they were checking what was wrong with him. I do remember that he had an endoscopy. [S] also had a biopsy of his tongue when he was seen at Guys Hospital because of the pain in his mouth caused by the ulcers. This was all as a result of the HIV infection. He couldn't eat because of the pain.
48. I was never given adequate information. I believe that [S] was used as a guinea pig for trialling the new drug AZT given to him for his HIV. Dr O'Doherty introduced [S] to AZT and we were never informed of the side effects or given adequate information.
49. After [S] died, two of my children were told about [S] HIV and infection and the cause of his death by doctors and both times without my consent.

Section 5. Impact

50. [S] was 7 years old when he was diagnosed with HIV. After the diagnosis [S] continued to attend St Thomas' Hospital because it had a specialist haemophilia unit, which he went to for his usual routine check ups.

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51. When [S] was 11 years old, we were told that his white T cell blood count was low. [S] seemed to stop growing. We were then told that he was going to be put on AZT medication to treat the HIV. Dr O'Doherty introduced [S] to AZT.
52. Everything went wrong and downhill from there. It was horrible, and I noticed the change in his condition soon after. After starting AZT [S] became noticeably ill. [S] became anaemic and he started to develop thrush in his mouth and when he was 12 he started to develop cold sores. The thrush progressed to ulcers in his mouth and [S] couldn't eat because of the pain. He was sent to Guy's hospital for treatment for the thrush and cold sores, where he had a biopsy of his tongue. We saw a lovely Consultant whose name I cannot remember who was so good to us. He said he would find something to sooth [S] mouth so that he could eat. He found a thick ointment, which gave some mild relief and expressed surprise that he hadn't been given any cold sore preventative medicine.
53. In January 1994, [S] became very ill, he had gone into hospital the year before and this is when he started his diary. He couldn't eat due to bad ulcers in his mouth. He was very small and very paranoid about not being able to eat. He weighed 5 stone when he died. His last entry in one of his diaries was on 12 February, he was quite ill by that time. [S] passed away on [GRO-C] 1994.
54. He kept the diary on his bed in hospital we didn't know what was in it. As I said earlier, my husband finds it too upsetting to look at and has not read it and I too, find it too upsetting. His diary entries are very personal.
55. [S] wrote a letter to me about AZT after seeing something on television and he told me not to read it until I got home. He wrote that he was scared and frightened. [S] had seen something on TV about AZT making people worse. He was scared. I showed the letter to

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Dr Gumpta and he came and spoke us about it. Then Dr O'Doherty and Chris Harrington came and spoke to [S]. They said that they thought the AZT had worked at the beginning but that it was no longer working so they stopped it. [S] was on AZT for two years and only stopped taking it 6-8 weeks before he died.

56. The doctors carried on prescribing the steroids after [S] came off AZT. At the same time [S] was taking iron for anaemia and a lot of morphine for pain medication. [S] was taking 12-13 tablets every day and towards the end of his life he spent most of the time asleep,
57. [S] was given Oramorph, because of the pain in his stomach, mouth and chest.
58. He kept getting a bad chest, coughing all the time. [S] went on to develop TB as one of the side effects of AIDS. He was getting a lot of bad chest infections. They said he had contracted a form of TB attributed to AIDS, not the sort that we would catch. Anything he got wrong with him was attributed to AIDS.
59. He also got lumps on his chest, which they thought were the ulcers. He had so many endoscopies but they were just getting bigger. They gave him steroids which I couldn't understand the logic of, as you hear about people taking steroids to get bigger.
60. Eventually the infection of his mouth ulcers travelled down to his stomach and he had to take steroids for it. Again, all I was told was that it was like a form of cancer attributed to the AIDS and it stopped him from going to the toilet. They gave him enemas to try to help as he felt so bunged up and uncomfortable. The days he could go to the toilet he was happy and he recorded this in his diary.
61. The doctors wanted to start radiation on his ulcer to shrink it. [S] had come home for the weekend on 16 February 1994 but we had to

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take him back as they were going to start the radiation on 17 February. But the ulcer in his stomach burst in the night, which is what he died from. [S] died in the early hours of [GRO-C] 1994, they used some fancy name for it on his death certificate. They recorded perforated ulcer and haemophilia as the cause of death. He was 15 years old. There is no mention of HIV or HCV on his death certificate.

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62. I really feel [S] was used as a guinea pig by the hospital for the AZT drug. It was only later that I found out that AZT was no good when taken on its own and it was discovered to be of no help and the side effects made people ill.
63. His brother is doing much better now and he was never on AZT. They never explained anything. All I was told was that [S] white blood cells were a bit high so they gave him AZT and that is when it all went wrong, from when they gave him AZT onwards. He started losing weight and everything went downhill.
64. We were not told about the side effects of AZT. They said it would help him. He had been taking it for 2 years when he saw something on the news and the things that had been written about it and he got frightened. He wrote a letter to me explaining how frightened he was and asked me not to read it until I was home. I told the doctors and they said they would talk to him and they told him they would take him off it because it was no longer helping.
65. They took him off the AZT 3-4 weeks before he died. Although I thought they were telling him a load of rubbish about the AZT it made him feel better after they talked to him. [S] wrote in his diary that Dr O'Doherty and Chris Harrington made him feel better because they said they were going to stop the AZT. To my mind the AZT made everything escalate so quickly.

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66. The way I see it, the AZT made everything escalate very quickly. After [S] had been on it for a while they began to see all the problems it was causing. Then it was one thing after another and they were giving him one set of tablets to counteract the other. They didn't take him off it until [S] saw it on the news and was worried about it. I seriously think that is what escalated [S] illness. Everything seemed to escalate and it was the AZT that made it all go wrong. Up until he was put on AZT everything seemed fine. I hadn't seen any problems at that point. He still had energy, he was still playing quite a lot and he was still quite chubby. They said they were putting him on it because of problems with his white cell-count. After that one thing after another happened.

67. Thrush of the mouth is quite common for someone with AIDS. In 1991 we went to St Lucia for 3 weeks and he got a cold sore. I've never seen anything like it and by the time we came home they spread all around his face. The doctor at home, whose name I can't recall, said that sun, can make cold sores worse. He couldn't understand why the hospital hadn't given him the preventative pill for cold sores, so he prescribed it for him.

68. In January 1994, [S] went into hospital and was in there a lot. The last couple of weeks he was having a lot of morphine and they were trying to cut it down to 100mg from 125mg as he was sleeping a lot. [S] was worried about this, and didn't think they should cut it down by that much because he was afraid of being in pain, he said that 100mg was going too far. [S] pills looked like Smarties, he would line them all up and we didn't know what he was taking because he was in control of his medication. At the end he was getting quite angry. If he heard anyone shout he would get quite anxious.

69. From January 1994 [S] was in hospital a lot. He didn't seem to want to come home and I got very upset. The doctor told me that sometimes this happened. [S] wrote in his diary that he hoped I

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would understand after. He wrote that he didn't want to come home and be in so much pain at home but he wanted to wait until he felt better. He was so frightened.

70. Dr O'Doherty said that he would not try to resuscitate [S] if anything happened to him because he said he had suffered enough. In my self I wanted them to do anything they could but they said he was suffering too much. He came home for the weekend on 16 February and we took him back to hospital on 17 February because they said they would have one try at shrinking his ulcer. We took him back to hospital on 17 February and he passed away on [GRO-C] 1994.

71. The nurse phoned my husband and asked him to come to see [S] as [S] was asking for us. He asked if it could wait until the morning because we were going there for [S] radiation of his ulcer. The nurse rang back half an hour later and said that [S] wanted him to come straight away but when ^{GRO-B} got there it was too late, he was met with a terrible scene, there was blood everywhere. ^{GRO-B} phoned me from the hospital and said that he didn't make it and that [S] had died. We comforted each other. Our baby was [GRO-C] and the other children were all asleep. The phone call was a real shock. ^{GRO-B} said that he was glad that I hadn't been there as it wasn't nice. The whole bed was covered in blood.

72. I woke my eldest up to look after the other children and I took a cab to the hospital. We were given no prior warning from the hospital. They rang at 3.00 am in the morning. He was fine the day we had taken him back to hospital, he was chatty, more than he had ever been and he seemed fine. He was talking about what he would get our baby when he was older. We didn't expect him to die at that point. Although he was really ill, in my head I wasn't accepting it.

73. One of the nurses (Heather) who used to look after [S] was on the ward the night he died but my husband didn't get to speak to her. She

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was like a second mother to [S]. Another nurse met my husband at the door and she told him that he didn't suffer, but he saw him lying in all that blood and he didn't believe her.

74. I sat with [S] until the nurse said we had to go. He had a sheet over him when I got there. We were there for about forty-five minutes. She made it obvious that they had to do things in the room and we could go and come back on the Monday to see him in the Chapel of Rest. He passed away on a Friday. She obviously had things to do in the room but didn't explain why. We were ushered out by the nurse. I asked Chris Harrington why it had happened but she said didn't know why. I always got the impression that once he died he could be forgotten about.

75. [S] loved his life. He loved Christmas. He loved school and was getting ready for his GCSE exams. He had the neatest handwriting I have ever seen in a child, he was also so meticulous. [S] attended [GRO-C] for his GCSE years. When he was in hospital he worried about getting schoolwork sent to him. He was really worried he was missing out and there was nothing I could do to get the school to send the work. In the end the hospital had to step in to get the work sent through from the school.

76. As I have already said, [S] diaries note very personal observations and comments on the treatment he was receiving, how he was feeling, his future aspirations and the pain he was in. He was looking to the future. Before [S] died I had been expecting a baby and [S] wrote about how he would look after the baby when he got better and how his brother would want for nothing when he was older. [S] died [GRO-C] after my baby was born.

77. The diaries were so neatly and carefully written, he was very tidy and he wrapped everything in tissue. They record his thoughts and feelings about his illness. He made an album whilst he was in hospital,

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everything was stuck in with captions beneath. He was into things like that.

78. [S] wrote that he had noticed that I had always treated him differently from his brothers and sisters. He noticed that I used to make him wear more clothes and would wrap him up, when the children went out.

79. [S] also wrote that he used to lock himself in the toilets at the hospital when he was in pain because he didn't want anyone to know. He wrote on the cover of one book that he would carry on writing in his book until the pages run out. **WITN268703** I said to my daughter that he never got to finish the book. He had noted future events such as my wedding anniversary. The red diary covers 8-12 February 1994 and records his future ambitions. He wrote about a future event on 20 February when he would be going to Planet Hollywood but he didn't get to go. **WITN268702**

80. His exercise book entitled, "My feelings and my life" was begun on 31 December 1993 and the last entry was made on 2 February 1994. **WITN268703** [S] wrote his final notebook entry on 12 February before he died on [GRO-C] **WITN268704**

81. Sometimes it is heart breaking to talk about what happened but sometimes it helps to say, "this is what has happened."

82. I later found out that [S] had been picked on and bullied by one of the boys at his school because he was so small. He would meet him at the school gates and make him empty his pockets. [S] never said anything to me about it. [S] kept all his paperwork in a tidy way and used to roll it up in an old Glennfidich tube to protect it. This boy took it away from him along with a special pen he had. He didn't want his brother to know as he would have gone and beaten him up and [S] would not have wanted that. We didn't know this was happening until I

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read it in his diary after he died. He wrote how he just wanted to be left alone to get on with his work and do his exams. He had told the school he was being picked on.

83. [S] school contacted us after he died and said they wanted to come to his funeral. I didn't want them at the funeral but my husband said I should allow them to come. I didn't feel that they cared enough when he was alive and this sudden show of care didn't feel genuine. They attended with flowers and some of the girls wrote a poem for [S]. GRO-B felt they had paid their respects and he thought it was quite nice.

84. The impact on our family life was horrible, it was terrifying and it was all you could think about at the time. If anyone got a cold I would be panicking. I was trying to keep what was wrong with [S] away from my other kids to protect him.

85. I have [GRO-C] other sons who are younger than [S] who both have haemophilia but they were given a completely different type of Factor VIII. I was more conscious of their treatment after [S] got ill and as a result of what happened to [S] I've got a thing about the Factor VIII products my sons have. When the hospital tried to change their treatment I didn't let them.

86. About 2-3 years ago the hospital wanted to change one of my younger son's Factor VIII treatment. My son was told by one of the doctors on the haemophilia side at St Thomas's hospital about his brothers having been infected with HIV and Hepatitis C and what [S] had died from. This was without my authority and this should not have happened but I didn't complain or say anything. I don't know the doctors name but It was one of the doctors he saw at his routine appointments.

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87. None of my younger children knew what illness [S] had died from. I told them he had died from cancer. The hospital had often referred to HIV and Aids as a type of cancer, so that is what we told our children.
88. My sister knew but it wasn't a case of going around telling everybody. We didn't experience anyone being nasty because nobody knew. It was horrendous on the television. We just had to get on with it. We didn't tell my daughter and my eldest son about their brothers having been infected. People treat you like a leper and there was stigma attached in those days.
89. My daughter found out from our GP without my consent when she was [GRO-C] years old in 1999 during her pregnancy. She saw [GRO-D] [GRO-D]. He told my daughter what [S] had died of. She came home and said [S] didn't die of cancer but died of HIV and AIDS. She was shocked so I told her what had happened and told her that it was a form of cancer he contracted as a result of HIV. I explained to my daughter what had happened and left it at that. I couldn't understand why he would have done that and I knew that he shouldn't have, but I didn't say anything because I didn't want to make a fuss, I was so stupid! My daughter honoured my wishes by not telling my other children. Since the Inquiry my youngest, who is [GRO-C] years old, has a suspicion but has not said anything.
90. Both my son and daughter found out how [S] had died against my wishes. I felt that my GP and the hospital had no right to tell my children how [S] died. My children were surprised that they never knew about it and that we had not told them but I didn't think it would do them any good to tell them.
91. The impact on our family life has been horrible. It was terrifying and all you could think about at the time. If anyone got a cold I would be panicking. I tried to keep his illness away from the other children to protect him but I don't think I did very well though as my daughter said

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- she always suspected something was wrong. If HIV was on the news or I saw something on TV I would be very vocal and I would get tearful and angry, so she suspected.
92. It might be 25 years ago but I can visualise it as if it was yesterday. Different things make you live it and you can remember all the things. Time doesn't heal and since the inquiry it has all started up again. I wouldn't say I had buried it. My husband and I started to get very emotional when I read the diary. You go to bed, you wake up in the morning and think, "if only." I tried to shut it out of my mind but since this inquiry it is all coming back.
93. When we used to go to the hospital we used to take down in the lift sometimes for chocolate but he couldn't drink it because his mouth was so sore and it all comes back, the memories.

Section 6. Treatment/Care/Support

94. I feel that the hospital should have given me more information about the illness and conditions in general.
95. Neither myself or any of my family has ever been offered any psychological support or counselling during his illness or after he died by either our GP or the hospital. I probably needed it. GRO-B wouldn't have taken it, because we deal with things differently. My husband says he has things to keep him occupied whereas I am at home. We relied on each other for support and we handled it.
96. None of my family has ever been offered a test for HIV or Hepatitis C.
97. I am a member of the Haemophilia Society but they never offered me, or any of my family any counselling or psychological support. We didn't

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have much to do with them. They got in touch when the boys were quite young. We received newsletters but nothing more than that.

98. It was [S] older brother who told me that there was going to be an inquiry. He asked if I had heard about it and then after he had gone I saw a news programme on television. They put pictures up and I got angry as I thought [S] should be there. We sent a picture in and they did put it up, although late.
99. We got a letter from McFarlane Trust at some point in the 1980s, which said they were going to give us 20k but we had to sign a waiver because they told us we couldn't fight the Government. I didn't have money to fight anyway. We wanted to take [S] on holiday and I couldn't afford that so we took the money. We also received £200 a month.
100. After [S] died I got a letter from Skipton Fund about an application for people who had contracted Hepatitis C. I didn't know that [S] had Hepatitis C. I phoned the hospital and it turned out that he did. Skipton were not surprised, they said that people who contracted HIV often have Hepatitis C.
101. It came as a shock to me. Not only did they infect [S] with HIV but also with Hepatitis C. His brother must have found out before I found out about [S] being infected with Hepatitis C, but he was an adult by then and not living at home. I only found out by chance about [S] when the Skipton Trust contacted me.
102. [S] brother only started taking HIV treatment a few years back. He wouldn't take anything before which I can understand because he saw what had happened to [S] [S] brother said he has never lived his life more than 5 years at a time because he never thought he would be there longer than that.

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Section 7. Financial Assistance

103. I received a letter from some solicitors advising me that the McFarlane Trust were offering us £20,000 but we had to sign a waiver form because they said that we could not fight the government. We took the money because we wanted the money for [S].
104. In 2011 the Skipton Trust wrote to me saying they were looking for victims who had been infected with HCV because there was a posthumous payment for those who had died of HCV. We contacted St Thomas Hospital on the advice of Skipton and they told us that [S] had been infected with HCV. Skipton Trust then applied to the hospital for [S] medical records in support of an application for funding. The Skipton Fund gave me an award of £10,000, that was it and we never heard anything more. There were no monthly payments. We were never told [S] had been infected with HCV whilst he was alive.

Section 8. Other Issues

105. I once read in the paper people with HIV should be left on an island by themselves. This was when I had only just found out that my boy had been infected with HIV. I always felt so upset how they could say that about my little 7 year old boy. He had nothing to be ashamed of.
106. I would like an answer as to why and how this situation could have happened. Nobody has ever said sorry for what has happened.

Statement of Truth

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

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Signed GRO-B

Date 16 04 2019