Witness Name: GRO-B
Statement No.: WITN3200001
Exhibits: None
Dated: 10th October 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

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

Section 1: Introduction

1. My name is GRO-B and my date of birth is GRO-B 1947. I reside at GRO-B GRO-B

2. I come from a large family with GRO-B sisters and one brother. My brother was a severe haemophiliac who died at eight years old from meningitis, at a time when there was no treatment and very little understanding of the condition. As far as I know, I am the only carrier of haemophilia in the family.

3. I have GRO-B nephews, none of whom have haemophilia, as well as GRO-B nieces. I was married for 48 years to my husband, GRO-B who sadly died two years ago. He worked as an GRO-B. I have two children; a daughter, GRO-B, who is 48 years old and was born in 1971, and my son GRO-B: S who was born in 1977 and who passed away in 1997, aged 19 years old. S had haemophilia.

4. In this statement I wish to discuss S's death as a result of being infected with HIV through contaminated blood products.

Section 2: How Affected

5. My son, S was born in 1977, and he was diagnosed with haemophilia shortly afterwards in March 1977. We noticed some bruising as a result of his standard injections and he was quickly diagnosed with the condition. He was cared for by GRO-B and found to have a Factor VIII deficiency in his blood. For his entire life he suffered with bleeding into his joints; both severe bleeds and spontaneous bleeds. The severity of the condition as well as the condition itself are hereditary and so, like my brother, he had severe haemophilia A.

6. S first started showing symptoms of bleeding when he was about 18 months old and he banged himself with a rattle. This caused severe bleeding we took him to the GRO-B for treatment. From this point on he began to be treated with Factor VIII blood products.

7. S's bleeds varied significantly, sometimes they occurred every few days, sometimes he went as long as six months without any flare-ups. In the event of a bleed we would take him in to the GRO-B for Factor VIII treatment immediately, and he often had to stay in hospital for as long as a week. We never treated him at home. S GRO-B dealing with his bleeds became something of a way of life for us.

8. S received dental treatment at the GRO-B On one occasion when he was approximately seven years old, I remember him having to visit the dentist as he had a milk tooth which was loose and continued to bleed. He was kept at the GRO-B for an entire week, with bad bleeds requiring Factor VIII treatment. At the time we thought that Factor VIII was a wonderful thing, as it allowed S to have a fairly manageable life. We did not realise that he was risking his life every time he received treatment.

9. On another occasion, when S was around eight years and nine months old, S was playing in the country lane outside our house when he was unfortunately knocked over by a car. He landed on the grass verge and was

immediately taken to GRO-B where he was given Factor VIII treatment and also stayed in for a week. He was kept under close observation and eventually recovered.

Diagnosis and Treatment

10. S continued to be treated with Factor VIII when he had a bleed. In November 1986, we were summoned by a letter to the GRO-B to see GRO-B. GRO-B explained to my husband and I, that S had been diagnosed with the antibodies to HIV. He did not explain anything about the infection, what it meant, or how to treat it and it was not until the media began covering the illness that we got any real information. We were not told about the risks of transmission to me or my husband. I have been tested for HIV and it was negative. I have never been tested for Hepatitis C.

11. He remained on Factor IX from then onwards, except for one incident where he was treated with Factor VII, and another when he was treated with the synthetic product Recombinant. Neither of those were as effective as Factor IX. S was only nine years old at the time of his diagnosis. I still do not know precisely when the contaminated blood was administered to him and he contracted the infection, because he did have Factor VIII treatment for most of his young life.

12. We tried to shield S from his illness, and for the first four years after his diagnosis he suffered from no symptoms of the infection. We had hoped that he was one of the lucky ones. However, in 1990, at the age of 13, S s kidneys failed and he had to be taken to the GRO-B once again.

13. Around this time, S was started on Azidothymidine ("AZT") treatment for the HIV infection. Looking back, it reminds me of the chemotherapy my husband went through later, and he seemed to have the same symptoms. S suffered from headaches, weakness, a loss of hair, shingles. I later found out that he had pneumonia twice but nobody told me this at the time. He also had encephalitis of the brain and used to suffer from mini-strokes and seizures.

14. The treatment regime for AZT meant administering the drug three to four times a day, but never at night. S spent three years on this drug. At some point the doctors tried to pair the AZT with another drug, the name of which I cannot recall, although this additional drug made absolutely no difference. I used to hate giving him these drugs and I could see that he had no quality of life. I remember one summer holiday wanting to take him into town, but I was not feeling very well and so I told him we would have to go another day. He said to me, "*Mum, I'm like that every day. I've got it all of the time.*" He got on with things, and he was not a complainer.

15. As the time went by, S got progressively worse. Eventually he did not even want to get dressed anymore as removing his pyjamas caused him too much pain. He also became increasingly reliant upon his wheelchair to get around, which previously he had only used when he suffered from knee bleeds. We tried so hard to keep him healthy, buying nutrients and aloe vera drink to help his immune system, and he used to eat small meals every two hours or so to keep his strength up. However, the more he ate the more he suffered, particularly from diarrhoea, and the longer he had to spend on the commode. In the end he was not having solid bowel movements and it was just yellow water, but I do not know if this was because of the infection or the medication.

16. In around 1996, when S was around 18 years old, I dropped him off at the GRO-B to have a meeting with GRO-B S went in whilst I was parking the car, and by the time I had joined them, they had been talking for some time. Whilst I had been out, GRO-B had informed S that he was suffering from AIDS. I asked GRO-B privately why he had told him and GRO-B had replied that he was 18 years old and he had the right to know. GRO-B believed S knew already. I had been trying to shield him from this, to protect him and I would have preferred to have been consulted. After this point S really went downhill.

17. I cannot remember being told myself that S was suffering from AIDS. The virus progressed and we saw him deteriorating. It seemed as though the doctors

thought it was obvious; that we did not need to be told it had progressed to AIDS. We knew already but we should still have been informed.

18. S rapidly began to deteriorate, to lose weight and he became weak, but we were not told anything about prognosis or what to expect.

19. Eventually, by 1995, we had to set up space for S to live downstairs. The diarrhoea had become a significant problem as it caused severe bleeding from his rectum. I remember the blood being like a tap; it was just an unbelievable amount of blood. He would sleep downstairs and would occasionally call up, "*it's started again*". He would faint through blood loss as we got him into his wheelchair. The ambulance always came when we called for it but he was in and out of the GRO-B an awful lot at that time. I recall a nurse having to cut him out of his pyjamas once, and there was so much blood that it seemed just like a horror film.

20. By this point I believe he was on heat-treated Factor IX. They also treated S with the synthetic drug Recombinant on one occasion, but that did not seem to be very effective. He was still suffering from strokes, from encephalitis and more bleeding.

21. In the last year of S's life, he was admitted to the GRO-B 28 times, each requiring around a week's stay in hospital. He used to hate going in on evenings and weekends because the GRO-B would be closed, and the other doctors on the ward would have to look after him and administer his drugs. He was given a room on his own, I assume because of the HIV, although this was never explained to us.

22. By the end of his life, the doctors told me that they did not know how long they could keep him going. He was very ill on that final day and I stayed with him, because I was told by the doctor's I might want to stay the night. My husband GRO-B joined us after coming from work GRO-B. I handed him a slip of paper saying that they wanted us to stay in, trying to keep this quiet from S.

23. I discovered that they had stopped treating S but I insisted that they keep giving him the Factor IX product. I wanted them to keep trying and they did provide treatment when I asked, but it was as though they had given up. As soon as the blood went in, it would come straight back out again.

24. S died at around 10am on GRO-B 1997. I tried stay with him for as long as possible, but I just could not watch him go into the body bag and I had to leave. We had learned while S was young how to manage haemophilia, and this treatment with blood products was supposed to help him, instead it led to a cruel and lonely death.

25. GRO-B came and checked his body and we were allowed to take him home. I know it was unusual to bring his body back home but S would have wanted it. I did not particularly want to, and I found it strange myself, but it was last thing I could do for him. I think that S would have wanted to come home, rather than be left at a funeral parlour.

26. We buried S in a cemetery GRO-B. He died on the Thursday and was buried the following Wednesday.

Section 3: Other Infections

27. I do not know if he was ever tested for Hepatitis C and I was never given any information about this. However, after S s death, we later received a payment for Hepatitis C, and so I assumed he had that too.

Section 4: Consent

28. We were not told of any risks at all associated with the Factor VIII or Factor IX treatment S was being given. We were simply told to take him to the GRO-B night or day if he bled. We thought we were doing a good thing by taking him in but we did not realise he was risking his life every time he faced treatment.

29. I sometimes felt that S was used like a guinea pig for treatment. No-one ever told us about the risks, and none of the treatment ever seemed appropriate for haemophiliacs.

30. We were also never told he was being tested. S used to have regular check-ups at the GRO-B every six months and they routinely took his blood, but we were never told what this was for nor were we ever given any of the results.

Section 5: Impact

Impact on S

31. S's diagnosis, and later death, had a huge impact upon all of us in the family. S himself was extremely stressed about HIV and the other infections he might have. I remember him once watching television when he was approximately 10 years old without me and a piece on Blue Peter about HIV appearing. He came in and told me that the programme had said that haemophiliacs were particularly vulnerable to HIV and he asked me if this meant that he had it. I told him that just because he had been exposed does not mean he had been infected. At this point he felt well, so he accepted it.

32. After S became aware of his diagnosis of AIDS he became depressed and went downhill rapidly. He would not do anything. He would not even watch the television, which he loved, particularly Eurovision. This was so unlike him as he was a really bubbly and positive boy. He never ever complained, and he really needed us to be positive for him.

33. I remember once being in the garden and a piece of paper falling out of S's window. I picked it up not knowing what to expect but on it was written "*I love life*". That was what S was like as a child at aged seven years.

34. S did not go on to further study after leaving school. It was impossible for him to study with the amount of pain he was in, together with his weak state and frequent visits to hospital. He always wanted to be a computer programmer,

though. He had an interview with GRO-B and was accepted, but we realised he would not have coped.

Stigma

35. After his diagnosis he faced a great deal of stigma from people who did not understand the infection or its transmission. I remember once being called into his school by his primary school head teacher when S was around nine or ten years old. The headmaster told me that I must instruct S not to share his drink carton with the other children, as some parents were concerned about the risk that he posed. This was a horrible thing to tell a child, as he only thought he was being kind. I knew that HIV could not be transferred like this but others did not and people only knew what they wanted to know. I did the research to find out about HIV but others did not.

36. Around the same time, when S was around nine years old and shortly after his diagnosis, we were admitted to the GRO-B He was fully quarantined, and the nurse treating him wore a mask, gloves and used disposable cutlery when serving S. I was sitting in the room the whole time and I was offered no protection, absolutely nothing. I thought *"I am a human being too."*

37. S was able to go to school and got nine GCSE's. Due to his infection he could not go out often but he liked computers and had decided that he wanted to study them. His head teacher in secondary school also called me to a meeting. When I arrived there were five teachers sitting in the office and I discovered that a mother of another child at the school had reported that S's pen nib had scratched her son, and this had caused her a great deal of concern. I found out later who it was and it was a friend of mine who had reported it. I asked her why she had not just come straight to me, as we could have sorted this out without getting the school involved. Either way it would have ended with me talking to S, whether the school were involved or not. I did not bother with her again after that.

38. I recall experiencing the stigma when I was at the GRO-B too. It felt like a very lonely place. I could never tell the other mothers what S was in the GRO-B for, and I know that S felt like an outcast, like he could not fit in with his peers.

Impact on family

39. S's death had a huge impact upon us all. His sister, GRO-B was always a deep, shy person and she never said much but I knew that she was afraid about catching the illness from her brother. There was six years between them and so they had never cuddled much, but I knew that GRO-B was scared.

40. GRO-B used to find it difficult when we had to move life around S's bleeds. We would plan an event and be all ready to go, when we would suddenly have to take S to hospital for a spontaneous bleed. I knew that this would upset GRO-B We tried to carry on with the plans afterwards and make it as normal as possible but this did not always work out. Some sisters stayed and helped out at the GRO-B but GRO-B was not like that, she hated having to go to there.

41. GRO-B used to have piano lessons, but I remember her piano teacher cancelling her lessons because he was worried about catching an infection from the keys. He told me that he had to think about his other students. I knew that this was not how HIV was transmitted, and that this was out of fear and ignorance, but this upset GRO-B who was only 15 years old at the time. She eventually stopped inviting friends around to the house.

42. GRO-B has never married and has never had children. I do not know if this was a result of S's death and for fear of passing on HIV. GRO-B has not been tested for HIV or Hepatitis C, but she did not have a lot of physical contact with S.

43. My husband GRO-B was hugely affected by S's death. He was quiet, and like a lot of men did not like to show his emotions, but he had lost a soul mate. He and S were very close and used to play and talk together a lot. The cemetery GRO-B was opened the year S was born. I remember

that GRO-B used to disappear for hours at a time and that I would find him in the cemetery GRO-B where S was buried, visiting him.

44. For me, life had become all about repairing the damage that had been done to S. It was about being there and being positive for him, always having a smile on your face when you yourself wanted to break down. You could not think of yourself, so you had to keep it in and eventually you keep it in for so long that it becomes difficult to let it out.

45. I cannot even describe the emotions that I felt. It was like losing a limb. Every day I think of him, that he should be married now or he should have children now, but he never got to live that part of his life. S was always looking at girls but he never got a chance to get to that stage and he used to think that he would never have a girlfriend.

46. I remember once dropping S off at Tesco, and whilst I waited in the car, he walked in alongside another boy the same age as him. I could visually see which one of them was ill. AIDS accelerates the ageing process and S looked like an old man next to the other young lad. AIDS is a very cruel thing.

47. I can also remember being upset by some of the treatment that we had from people at the GRO-B Immediately after S's death I had to ask a nurse to leave, as she had come into the room and was fussing about us, dusting while S's body was on the bed. I thought this was so insensitive. GRO-B Social Worker, also came to visit us and was discussing funeral arrangements whilst S was still in the room. To her credit, she realised this was insensitive and took me to the office where we had a discussion that was helpful.

48. I did not want to bring S's body home after he died but I knew that he would have wanted it and it was the last thing I could do for him. He looked so peaceful in the open casket, but a local vicar visited us and said, "*some people would think that was abhorrent.*" It was very hard for me but I wanted to do this for him.

49. So many people came to his funeral. I think it was because he was so young. Many of GRO-B's friends and clients came as well. GRO-B said to me no-one will ever forget S because he was so young when he died.

50. The grieving goes on and I just tried to deal with it. You take each day as it comes and you tell yourself that it's going to feel okay, but it will take time. You have to keep reminding yourself that it will hurt less and that one day the loss will not be so deep. It's like it happened in another life. In a way we were lucky, as S never ever felt sorry for himself, and I do not think we could have coped if he had been the sad type. Without S being so strong, we could not have coped.

Section 6: Treatment, Care and Support

51. We were never given a great deal of information about how to treat S by the doctors. Long after his diagnosis we had a chat about transmission but only later, and for a while we only had the media to go by. It was as though no-one knew how to handle it or what they were doing.

52. S was never offered any medication for his HIV until he had kidney failure. It was like the doctors did not know what they were doing and that they did not have any guidelines to help them. It was as though they were saying, "*we'll see if this works*", and that it was something new for them as well. I was not confident in them, and we did not know if the treatments would work or what the side effects would be. After seeing what the drugs did to him it felt awful giving him the medication.

53. We were offered some support at the GRO-B in the form of social workers, but S did not want to talk to them and they were not very helpful for him. It made him remember what he had and what could happen and he just wanted to try and forget. I also went to some of the group meetings, but when I came out I thought "*sorry I feel worse than when I went in. If that's therapy, I don't want it.*" I am like S in that way.

54. There was team in GRO-B which offered things like aromatherapy and reflexology for AIDS sufferers but this mostly catered for the gay community and S did not particularly want to be associated with that. There was absolutely nothing available for the haemophiliacs to use.

Section 7: Financial Assistance

55. In 1992 when S was about 15 years old, the Government introduced the Macfarlane Trust organisation, which organised some weekends away. We learned about the Macfarlane Trust from The Haemophilia Society. These weekends included aromatherapy and reflexology and other things like that. S really did not want to get involved, as it was mostly for older people, and when he went it made him aware of what could happen to him. He only went to two of these weekends. The weekends away that S attended were paid for by the Macfarlane Trust. They also provided £1,000 towards his funeral costs.

56. The Macfarlane Trust did not make it hard to get the payments, but they certainly did not go out of their way to help either. It was as though they had the money but were waiting for the victims to die, so they did not have to give as much of it out.

57. The Macfarlane Trust was good for little contributions, but you always had to go to them to apply for them. It felt like a lump sum would have been better. Constantly going to them and asking for money was demeaning and it felt like we were money grabbing.

58. At some point we received a pay-out from the GRO-B for £20,000 in relation to Hepatitis C. This was the first time I had ever heard about S having Hepatitis C and so I have to assume that he had it and that we were never told. We were only told of this by letter which is a very upsetting way to be told. It felt like poor S had everything going.

59. I think GRO-B had to sign something but he took care of all of it and so I am not sure. I do not recall having to sign a waiver in order to get this payment, but it certainly felt it was a way of getting us to shut up, a one-off thing to brush us under the carpet. In fact, I thought all of this had been done and dusted, and the payment certainly gave us that impression.

60. My husband GRO-B took care of most of the finances and so I am not sure of the details, but I do recall we eventually received carers allowance, although only after the second attempt. A social worker helped us get this allowance. We had applied for it earlier, but it had not been granted.

Section 8: Other Issues

61. I hope that this Inquiry can help us obtain an apology for what happened, and importantly make sure that it never, ever happens again. I want to put S front and centre and ensure that we can finally get some answers.

Statement of Truth

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

Signed GRO-B ....

Dated...10th October 2019.........