Witness Name: GRO-B
Statement No: WITN1656001
Exhibits: WITN1656002 - WITN1656003
Dated: April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B and I live at GRO-B GRO-B I was born on GRO-B 1957. I married GRO-B: H in GRO-B 1979 and we had GRO-B and GRO-B on GRO-B 1983. I remarried in 1994 and we have a daughter. I am a foster carer and currently foster 2 boys.

2. This witness statement has been prepared without the benefit of access to my late husband's full medical records.

3. I am aware that my 2 sons, GRO-B and GRO-B and my brother in law, GRO-B: B (who was also infected), and his wife, GRO-B and my nephew GRO-B all intend to provide statements to the Inquiry.

Section 2. How Affected

4. I am providing this statement to the Inquiry on behalf of my late husband, H who had severe Haemophilia A and was infected with

HIV, Hepatitis C (Non A Non B) and Hepatitis B (which he cleared naturally in his teens) after being given infected blood products (Factor VIII). He was born on GRO-B 1952 and died of AIDS on GRO-B 1992 aged 40. However, AIDS was not recorded on his death certificate, which I exhibit at WITN1656002.

5. H was a Haemophiliac and I knew this from when I met him. We first went out in 1978 on New Years Eve with B who is H younger brother and GRO-B (B wife). We were all good friends. Normally all 4 of us (H, me, B and GRO-B would go to the hospital for appointments together and we would be seen in pairs.

6. H was treated at the John Radcliffe Hospital, Oxford as a young boy which was the only centre in the country at the time that could deal with it. He then moved to the Royal Infirmary at Cardiff under Professor Bloom. He transferred to the Heath Hospital in Cardiff when this was built, and was still under Professor Bloom.

7. In his notes I believe that H was given infected blood products in 1979 when he was around 26 or 27 years old.

8. I believe that in or around July 1984 we had a phone call and a letter from Cardiff Hospital asking us to come in to discuss the blood products that H was taking. H was around 31 years old. B also had a call to go in. My mother came to look after the boys and all 4 of us travelled to the hospital together.

9. When we arrived at the hospital, there were another 3-4 couples in the waiting room and H and I went in first. We saw Professor Bloom and Dr Dasani, who was the Clinical Assistant to Professor Bloom, was also present. Professor Bloom explained that there was bad news as H had been infected with something and he did not think the chances were good for H Professor Bloom and H were close and had developed a relationship over time, so H expressed that they had beaten so many

things together that they should be able to manage something else, however, Professor Bloom said he did not think so this time.

10. He said he was *'damned if I do, damned if I do not'* and he said that knew something was wrong with the blood but still had to give it to H as he needed the Factor VIII for his Haemophilia. Professor Bloom said he did not have a choice other than to give H the blood product. He took a risk and he did not inform us of it.

11. Professor Bloom spoke about the blood coming from America and the background of why the NHS needed the blood as they did not have their own Factor. He then said how HIV can be spread. We were told there was a risk of H infecting me. Professor Bloom told us to be very careful and always wear a condom as then it could not be passed on very easily.

12. At the end of the appointment they told us not to discuss it with anyone else. Everything was kept very *'hush hush'* like some sort of '*dirty secret*' and we were told not to discuss it with anyone until the doctors knew more about it. We were told to not even tell family. Professor Bloom even told us not to tell B but H was so close to him they were always going to discuss things.

13. We were never in the meetings for long; perhaps 30 minutes. They did not give too much detail as they said they did not know much themselves. It was very scary and our lives completely changed after that meeting.

14. After H knew he had an infection and there was a risk that he could give to me, we were worried. Due to this risk of passing it on we did not have a sexual relationship after this as we could not leave the boys without a mother and a father. He was very strong willed.

15. At the time, H and I felt that Professor Bloom had given us enough information to manage. It was later, after learning more, that we realised that Professor Bloom did not do enough. The meeting was quite blunt and we

were just told straight away. We did not appreciate how massive the implications were. Then we saw all the TV adverts and media propaganda. H was frightened and it made him feel unclean. We felt really isolated and did not know that other people were involved until Gareth and Hayden at the same Haemophilia Centre set up the Birchgrove Group and we went along to meetings.

16. I believe that H actually contracted HIV in or around 1979, when he was about 26 or 27 years old, which was around the time when we were trying to have children. I think it is in H notes so I assume Professor Bloom told us that was when he was infected. If we had known before we would not have taken the risk about having children.

17. I definitely believe that they knew that H was infected before they told us. I exhibit a letter dated 21 June 1983 confirming his blood was tested for an acquired immune deficiency syndrome as part of a survey of severe Haemophiliacs at exhibit WITN1656003. I know for a fact that it was at least a year before they told us. This information should have been provided earlier. They knew what they were doing was not right and they knew they could have been giving some other Haemophilia treatment.

18. We had had a meeting with Professor Bloom earlier, in the summer of 1979 before we got married, as we did not want to have bleeders due to the amount of treatment that H needed. Professor Bloom said it was fine to try for children and that they could not have Haemophilia. We would not have had children had we not got the all clear from Professor Bloom.

19. Professor Bloom was like a God in that hospital. He always had an entourage of at least 8 or 9 people with him.

20. Further details of how H was infected are detailed in his GRO-B B B statement.

Section 3. Other Infections

21. As far as I am aware H suffered from no other infections.

Section 4. Consent

22. I believe that H was tested without his knowledge as I have been told by B that on one occasion when H and B went to have their blood taken they were told that 5 vials had to be taken for the purposes of giving them the AZT treatment. Dr Dasani then came back in and said he needed to take one more vial of blood. B questioned him as to why and he replied that he had forgotten one. B told me that Dr Dasani kept this last vial of blood separate and said it would not go to the laboratory as it was for their own separate '*special research*'.

23. I do believe that H was tested and treated without his consent and without adequate information being provided to him.

24. H was part of the AZT drug trial along with B They stopped it when he became really ill. It was only when they took him off the trial that we could ask whether he had been given the drug or the placebo and we were told that he was on the placebo. They played a game; it was an experiment as his brother had AZT. I therefore believe that H was tested and treated for the purposes of research.

Section 5. Impact of the Infection

25. Finding out about his HIV infection really took the wind out of H sails both mentally and physically. He aged overnight. His personality changed from being very easy going and laid back to constantly worrying and being paranoid with personal hygiene in particular; he used to do everything himself to avoid any risk of infecting anyone else. He was also very moody when he became really ill towards the end we started to argue more often, something that we never used to really do, so I knew something was not right. H also developed a tremor shortly before he was diagnosed with HIV.

26. He became quite depressed and got down about his infection. He worried about leaving me and did not see a future. He had no life insurance or anything and worried about our finances.

27. He was also very concerned with people finding out. He was worried about how people would react to our children if they found out. He became a recluse really. He did not want to leave the house when he thought he looked ill and so he would rarely leave the house at all. He used to love going to the bookies and placing bets on horses and used to love fishing too. All these things stopped as he got more ill.

28. He only had one friend called GRO-B who he told about the infection; GRO-B was the only person outside the family to know about it. He visited H when he was ill and visited us after H had passed away.

29. He had no personal life and we had no sex life from around 1984 when he was told he was HIV positive.

30. H was also very concerned about his brother and he worried about B constantly. H was the eldest child and was 16 when his mother died, so he helped to bring up his siblings, including B who was 7 years younger than him.

31. On his GRO-B birthday in GRO-B 1992, which was about 2 months before he died, I remember taking pictures of him and going to town to get them developed. I remember looking at the pictures on the way home and this was the first time I saw he looked ill. I nearly passed out in Station Road. He looked so different and his jaw had gone down but seeing him everyday, I did not realise and had blinkers on. I did not want to accept it and fought it to the end. I kept on thinking that he would beat the infection as he was a fighter but he did not. He lost a lot of weight and lost his appetite completely.

32. He would still enjoy getting a takeaway and eating with the rest of the family but then he would just throw it up straight away outside the bathroom; he could not even make it in. He loved a takeaway though so would still eat it knowing that he would later throw it up. He was housebound.

33. He loved our children so much and always called the children '*my boys*'. He idolised them. When they were younger he would play-fight with them but he became cautious and did not like close contact in case of transmitting his infection to anyone. He really changed due to it and became more reserved and stepped back.

34. He had his own cutlery and we were told my Professor Bloom to use different utensils and towels for him. He even wanted to sleep in his own bed to protect me but I did not let him. H was isolated.

35. People assumed that he had cancer and so we went along with it. Even when he passed away people all thought he had died from cancer; I never corrected them. To this day I do not tell people how he really died.

36. My whole life was, and in some regard still is, a lie. I cannot tell even my close friends about H infection and it is bad.

37. After a while, H could not walk and he was in a wheelchair for a lot of the time. His sight and vision became very bad and he had blurred vision. They boys used to go in and show him things like pictures they had drawn but he couldn't see. He had also developed PCP pneumonia and he really suffered badly with this, and from terrible eczema.

38. When he was well he was 5'6" and 9½ stone. He wasted away in front of us. When he died he was only 5 or 6 stone; down from about 8 stone. When he was very ill I could lift him out of bed and put him in a chair to strip the bed.

39. He did not drink alcohol and he had no interest in food for a long time. If he did eat it would only be because he thought he had to. I was angry at the

situation H was in but H was always calm. He was one of the bravest men I have met and he never complained. I used to just question why he got this infection in the first place.

40. H speech was bad when he became very ill and he would slur his words.

41. H started the AZT trial drug but it was stopped when he became really ill. We were then told that he was actually on a placebo. H therefore never got any treatments as he was on the placebo AZT trial drug.

42. He was also on anti depressants while he was ill.

43. H also had bad teeth and he hated the dentist.

44. H wanted to die at home. Dr Dasani got in contact with my GP, GRO-B GRO-B and they looked after H all the way until the end. Dr Dasani would come out to see him and he even got H his own room in hospital when he would have to go in. Nurses came to the house from the surgery and the hospital and they were so kind to him and gave him such wonderful care.

45. H was brought home in August 1992 and he never had a bleed or injection at all. I did have to fight against my mothers wishes to bring H home, as she was still living here at the time, as she was very worried. She was from a different generation where she was too aware of the stigma around HIV. She did not know how the virus could be spread or anything. But I told her that I had to bring him home and she helped me with the boys at home and my sister took them to school. He knew he was dying and asked the boys to bring catalogues to him so they could choose their Christmas presents.

46. In reality I lost H 4 years before he actually died. We lost any quality of family life. We had no more family holidays or even meals.

47. I got tested every 6 months after H got ill, to check that I had not been infected too.

48. H was cremated as per his wishes. He did not want to be buried near us so that we would always pass the cemetery and think about him and what happened. He always said that he did not want a headstone or anything. I am not sure that he was allowed to be buried anyway.

49. Even the funeral was not normal. A lot of funeral directors would not handle H body. He had to have a closed sealed coffin at the house. When my dad had died he had had an open coffin in the front room, so it made me feel that H was dirty. I was distraught and couldn't get my head around the fact that he was dead.

50. H was so well known; everyone knew the family and the funeral was packed; we could not even fit in the church. This made things harder knowing how many people cared for him.

51. For 2 months after H died I could not do anything and I could not leave the house. My sister would do everything for me; shopping and all. After 2 months she refused to do all these things and said I had to get back outside and do things for myself again.

52. The boys suffered badly from all this too. GRO-B and GRO-B had slightly different reactions but they both had a mutual anger from the situation. Every door in my house had a hole in from the boys punching them. GRO-B became very quiet and withdrawn and GRO-B turned to alcohol and drugs. It was very had to deal with and seeing them in such states was not easy.

53. I told GRO-B when he was 18 years old and GRO-B when he was 21. GRO-B found a lump on his body and was so upset as he thought that he was going to die of cancer like his father. I had to tell GRO-B the truth but I made him promise not to tell GRO-B as GRO-B was not in a good place at the time, taking drugs and drink. GRO-B is currently on anxiety and depression medication. He still becomes very withdrawn on this topic.

54. After he died I used to take the boys to the cemetery where the funeral service was on Christmas Eve for 2 years, but GRO-B would jump on every gravestone on the way out. He was just furious. After 2 years I had to move the visit to the week before Christmas as it ruined our Christmas.

55. His death was life changing for us all and he was and is truly missed. We felt safe with him in the house. It was and still is a massive loss to us. I still have H photo in my bedroom.

56. H always told me not to stay alone. He wanted me to remarry and give our boys a father again.

57. H GRO-B brother GRO-B died a year before H and I believe H heath deteriorated even more rapidly from this point.

58. After I remarried in 1994, it became harder to see my brother-in-law B and his wife GRO-B as it would just remind us all of H The family grew distant for a while. Before this, we were all very close and used to go out regularly for family meals together as H especially was very family orientated.

59. The stories we heard of people suffering from HIV stigma terrified us and so we would always keep H infections to ourselves. H was in hospital at the same time as Colin Smith and I remember his mum saying they had sprayed 'AIDS' on the side of the house. It terrified me. We were, and still are; very conscious of this and so we have been careful not to tell anyone. Even now we have to be careful with our reactions to news about the Inquiry as people could get suspicious.

60. The school the boys went to was good and they did offer to help us and pay for school trips for the boys if I could not afford it after H died. They were very considerate.

61. The boys did not accept my new husband GRO-B as a step father or even a father figure.

Section 6. Treatment/care/support

62. Dr Dasani and a few of the nurses at the hospital were very good. They all came to his funeral too. The care and support from the hospital was very good.

63. Linda Ford was a Haemophilia social worker for us. She came to support H in regards to money and benefits and she did all this on her own back which was really appreciated.

64. Neither H nor I received any counselling.

65. In 1994 I arranged counselling for my sons GRO-B and GRO-B I had to go and organise this myself. However, GRO-B and GRO-B refused to participate in the sessions as they did not like being told what to think or how to feel. They wanted to do this on their own. The psychiatrist said there was nothing that they could do for the boys as they would not open up and talk.

Section 7. Financial Assistance

66. Both H and B were part of the 1991 HIV litigation but both of them refused to sign the waiver. We had to go to a long meeting at the Copthorne Hotel and they stood us up and called our name like cattle and asked if we were married and had kids in order to determine how much money we would receive as the payments were means tested. There were over 100 people in the room and we knew most of them. It was all in public so we had to do this in front of each other. This was in January 1991. We all thought we were going to die so it did not matter to us that it was not in private.

67. H then got £60,000 from the MacFarlane Trust, even though he refused to sign the precondition

68. Later he received £20,000 from the American litigation, as did B We signed the precondition here.

69. After H died I received £10,000 from the Skipton Fund as Hepatitis C bereavement money. I found out about this being available from B

70. H never found out he had Hepatitis C too as he passed away in 1992 and B was informed of this later on.

71. I was also getting monthly payments too until I got remarried. The precondition was that if I did get married again then the payments would stop. I do believe that this was unfair; however, as the money should have continued in order to support our children until they were 18, even if it was lessened for me.

72. I would not have known about the £10,000 payment if it was not for B

Section 8. Other Issues

73. It is so hard to keep revisiting all these memories. I just want to be able to have some justice in order for us all to have closure. H deserves closure in order for us to be able to lay him to rest once and for all. I only want to remember good memories of him and not keep going over these negative memories of the bad times.

74. We will not ever really accept what happened and you cannot really pinpoint one person, even if they are alive now. They knew and they played Russian roulette with peoples lives.

75. We were never made aware of any risks throughout everything and even with the AZT treatment; only half of the people actually got the drug.

76. Every other country has dealt with this scandal and it is finished with. We are still going and still having to relive this all. They obviously do not want to admit it and open the flood gates; I do not believe that they will ever really fully admit it.

77. Documents have been going missing and things have been getting lost. It is evident that they are still dragging their heels over this and people are still losing their lives.

78. People know they are not going to see the end of this and it is worrying; there is no end in sight. They do not see the damage that they have done; we are just numbers to them.

79. I had cancer 3 years ago but had to fight hard to make sure that my boys are not left without any parents. I was worried about having chemotherapy and had doubts in my mind due to H and what they did to him. I have no trust in the NHS anymore.

80. It toughens us up and closes us up with our lives and families and kids.

Anonymity

81. I wish to remain anonymous as I made a promise to H

82. I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed. GRO-B ....

Dated.......29/4/19.....................

Medical Chronology

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the statement)

19/6/1966	letter from Dr Bloom. This patient recently attended for the first time with the diagnosis of severe haemophilia which has been confirmed. He is in need of dental attention and I should be most grateful if you would arrange for him to be seen
2/6/1975	treatment of bleed with cryoprecipitate
28/6/1976	now on home treatment
27/9/1979	refused to attend dental appointments out of fear
22/11/1979	Dental Hospital Cardiff. Requires a full dental extraction
July 1984	known to be HIV positive per Dr Dasani letter 18/12/1989
1985	HIV positive. HCV positive
12/3/1987	counselled re AIDS. Test info
23/10/1989	clearly his present skin disorder is related to his virological positivity. It can be classified as a seborrheic dermatitis, although it looks quite psoriasis form in areas
1989	Concorde AZT / Placebo trial
18/12/1989	Letter Dr Dasani. He has known to be HIV Positive since July 1984
Dec 1989	presented with neurological symptoms of diplopic loss of co-ordination and impaired cognitive function
11/12/1989	AZT started. Stopped
7/5/1991	letter Dr Dasani. Developed AIDS in December 1989
2/5/1991	letter from Medical Research Council Janet Darbyshire. We discussed him at a recent meeting of French and UK independent panel of HIV experts who verify the progressions in Concorde. We felt this case was somewhat unusual as the patient has now done very well for over a year although the initial diagnosis was PML
Aug 1991	on DDI (Alpha trial)
20/2/1992	trans bronchial biopsy positive for PCP pneumonia
March 1992	?fungal pneumonia

10/4/1992	AZT reinstated. Stopped 29/4/1992
7/8/1992	Mycobacterium Avium Intracellulavae isolated from two sputum samples. Went home. Progressively weaker and wasted. Bed bound