ANONYMOUS

Witness Name: GRO-B
Statement No.: WITN3549001
Exhibits: None
Dated: October 2019
29·10·19

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

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

Section 1: Introduction

1. My name is GRO-B My date of birth is GRO-B 1948. I reside at GRO-B. I am making this statement in respect of my late husband, GRO-B: H I make this statement from my recollection of events. I did request H medical records, but I have not yet received them.

2. I met H whilst I was training as a nurse and we got married on GRO-B GRO-B He was a friend of a friend. We had two children, a son and a daughter. My son does not have haemophilia. My daughter has 33% clotting and she has tablets to control this. She has not had any Factor VIII because she does not have any spontaneous bleeding. I have one granddaughter called GRO-B who has also been tested and is not a carrier for either haemophilia or GRO-B GRO-B, which I discuss later in this statement.

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Section 2: How Affected

Haemophilia

3. H was diagnosed with haemophilia A and it was severe. He had 2% clotting and I was aware that H had haemophilia when I met him. He was diagnosed when he cut his leg at the age of two years old and they could not stop the bleeding. H grandfather was also a haemophiliac.

4. For treatment, H had fresh frozen plasma from a young age and he was around 20 years old, in around 1970, when he first received Factor VIII; he took it as soon as it was made available to haemophiliacs. We were already married when he first received Factor VIII.

5. H had spontaneous bleeds at times, in particular in his kidneys and into his joints. Before treatment with Factor VIII in particular, H was frequently hospitalised. He would usually attend Walsgrave Hospital ("Walsgrave") in Coventry (now part of the University Hospitals Coventry and Warwickshire NHS Trust). We were never given any information or advice about the severity of H condition and we were left to get on with managing his condition ourselves.

6. I recall one incident when he was digging in the back garden and both his knees swelled up. Before this incident, I do not think I appreciated the severity of H condition.

7. H also had three cousins with haemophilia and they all contracted Hepatitis C whilst being treated in Coventry. H nephew also contracted HIV in London. H nephew was told this was caused by him sleeping around, but he was a Christian and a virgin at the time he became infected, so that could not be right. H nephew nearly died and I told his mother, H sister, to take him to Birmingham and ask for the most senior doctors at the hospital to treat him. He is now on treatment.

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GRO-B

8. H also had GRO-B and this complicated his treatment for haemophilia. The cerebellum at the base of the skull supplies all the nerve endings to your body. GRO-B causes the cerebellum to deteriorate, causing the nerves to die, and then whichever part of the body they control stops functioning. He was given six months to live at the age of 30 because he had cardiomyopathy and his heart was in such poor condition. Sadly, by the time H died his legs were paralysed and he only had limited movement in his arms. He was also profoundly deaf due to the GRO-B

9. When I was pregnant with our son GRO-B I was told to terminate the pregnancy due to the risk of passing on GRO-B. I was put under pressure to do this at Walsgrave and I was told that I would give birth to a "freak". I went to London to a specialist centre and I saw a Professor there. H and I were only young at the time, I was 23 years old, and I was told by the Professor that there was a one in ten chance that my child would be disabled. He gave us the support we needed in order to continue with the pregnancy. They did offer to test me to determine the sex of the baby, and if it was going to be a girl, they suggested I should terminate the pregnancy to avoid her being a haemophilia carrier. I refused.

10. Both haemophilia and GRO-B are congenital. It is very rare, and unfortunate, for somebody to have both GRO-B and haemophilia like H did.

Treatment with Factor VIII products

11. Initially, H had a severe reaction to Factor VIII. He would go into shock, he would go grey and his breathing would be affected. We told Walsgrave about H reactions and they said it was in my imagination. However, given his reaction, I did not feel comfortable giving him Factor VIII at home.

12. H reaction to Factor VIII worsened and he began to have minor cardiac arrests. He was admitted to Walsgrave and placed on a heart monitor which

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recorded that his heart was severely reacting to the Factor VIII. We were told H was allergic to Factor VIII and it was affecting his heart. This meant he was given Piriton 8mg intravenously and Hydrocortisone 200mg intravenously very slowly, before Factor VIII was administered, which was also given very slowly. This seemed to counteract the side effects and following this I felt comfortable administering his Factor VIII at home.

13. Despite the allergic reaction, H wanted to be able to have Factor VIII at home rather than travelling to hospital, when he had a bleed. I was trained as a GRO-B and able to do this. I was not given any separate training to show me how to do this, as I did not need it. If there was a problem with H treatment, Walsgrave GRO-B and in an emergency we would go to the hospital. I recall the first time that I administered H Factor VIII at home with Piriton and Hydrocortisone, I asked a neighbour to come over for moral support.

14. H had lived his whole life in GRO-B. After we were married, we lived there until 1997 when we moved to GRO-B. We lived in GRO-B from 1997 until his death in 2002.

15. As a result of H dual conditions of GRO-B and haemophilia, he was sometimes taken into hospital as a precaution. He was frequently kept in a side room, which at the time I thought was very kind. However, on reflection, this may have been the time that they knew he was infected with Hepatitis C.

16. I recall on one occasion, H scrotum became swollen and sore and I had to take him to Walsgrave. I cannot recall the date of this incident. We were told this was a spontaneous bleed, but he was given antibiotics to cover a potential infection. He was discharged quickly with a week or two of antibiotics. Unfortunately, following the course of antibiotics, H scrotum then swelled up again and I had to take him back to Walsgrave. Unfortunately, as a Registered Nurse in GRO-B, I knew all of the nurses at the hospital.

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17. The nurses at Walsgrave told me that I must have being infecting him during sexual intercourse. I thought "*how dare you!*". He was too swollen to even attempt sexual intercourse in any event.

18. H GRO-B was treated at the National Hospital for Nervous Disease in London, and I requested an ambulance to take him there. I thought they would be able to tell me what was going on. I was told that I did not need to do that and instead they prescribed H a maintenance dose of antibiotics for six months, which helped with the swelling. After six months the infection had cleared and H continued to have Factor VIII whenever he had a bleed; H bleeds were frequent. We carried on life as normal.

19. Since discovering H was infected with Hepatitis C, I have often wondered whether H became infected around the time of this incident, but I have not yet been able to obtain and review H medical records to ascertain this. I do not recall the batch numbers or types of Factor VIII that H was prescribed. I do recall that the bags had labels on them but I did not take much notice of these at the time. It may be that these batch numbers can be located in H medical records.

Diagnosis with Hepatitis C

20. In 1998, after we had moved to GRO-B, H was hospitalised at the Queen Alexandra Hospital, due to a severe bleed. On H discharge note from the hospital in GRO-B, it said H had been infected with Hepatitis C. I said to the doctor: "*what are you talking about?*". The doctor told me that H contracted Hepatitis C in Coventry.

21. I rang Walsgrave and spoke with Sister GRO-D, a haemophilia nurse. I asked her whether H had Hepatitis C and if so, why were we not told at the time they diagnosed this. She said that I was not told that H had Hepatitis C because "*with* H GRO-B *and cardiomyopathy we didn't want to worry you.*" I said to her "*God forgive you, you could have left me and my children open to infection.*"

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22. We were not given any further information about Hepatitis C at the time, including the risks of transmission, and I do not know when H contracted the infection, when or how he was diagnosed. However, because I was a Registered Nurse I did know that blood may contaminated with Hepatitis C and I was always very careful to keep everything sterile. I always used bleach to clean our home thoroughly and I kept any bodily fluids from H away from the children.

23. Around this time in 1997, I gave up nursing, at 49 years old. I had decided to nurse H at home. I felt at the time H was suffering from loneliness, fear and he was suicidal, so I thought giving up work would help him. At the time, the children were also living at home.

24. Between 1997, the date we found out about H diagnosis, and H death in 2002, H was not offered any treatment for Hepatitis C. We enquired about treatment but we were told it would be too severe for H due to other complications. I think the combination of Hepatitis C, haemophilia and GRO-B made it more difficult to treat H. It did affect his medical care.

25. Dr Green, a consultant at St Mary's Hospital and Queen Alexandra Hospital in Portsmouth, was brilliant. He did not give us any advice regarding Hepatitis C as he just assumed I knew it. However, he acted as a co-ordinator, because H needed a number of different consultants with different specialisms, and he was really very good.

26. H was given some treatment for his symptoms and for the last year of his life he was on a sub-cutaneous pump with morphine injected into the abdomen. In around 2000, the GP and the nurse visiting H would not take responsibility for administering H Factor VIII and they told us that we had to go to Queen Alexandra Hospital in Portsmouth. H was so poorly and he did not want to be in hospital, so I decided to nurse him at home with a District Nurse. Later that

year they took H off the sub-cutaneous pump and they put him on morphine tablets instead.

27. In 2000 H was 50 years old and he was classified as terminally ill. We had a wonderful social worker and we had carers that came in every night to help me care for him. The social worker arranged for the carers to come in. H had needed oxygen at night for quite a few years. He was sleeping on a hospital bed in the front room of our house and I would sleep on the couch until night carer's were provided to help us.

28. I would assist the carers at night. Fortunately, my brother came over from GRO-B for six months to help me to cover the nights as well. During the day, we had carers and again I was able to assist.

29. Throughout 2001 we were not offered any respite care because nobody wanted to take him on. He was then moved into a disabled unit and I was told that, because of H multiple conditions, the carers would have to go with him for respite care, and if he had a bleed he would be taken straight into hospital. I had called for a meeting with one care home to explain about H Hepatitis C and the best way to deal with blood.

30. Throughout the last two years of his life, a District Nurse visited and we had regular help from extra carers because he had been diagnosed as terminally ill by Queen Alexandra Hospital and St Mary's Hospital in Portsmouth.

31. Shortly before he died, H told me that he was tired, worn out, and he was unable to look after me and the children any more. My brother GRO-B, flew over from GRO-B on GRO-B 2002. This was unexpected, but he told me that he had a feeling he needed to visit, so he did. I said to him at the time that H was well, we were doing okay at the moment but we were pleased to see him.

32. The next morning, on GRO-B 2002, one of the carer's called me and said he was having a turn with his heart and was unresponsive. We had a MARS

resuscitator at home. We could not perform external massage due to H haemophilia, but we would attach the resuscitator so that he did not suffer brain damage when he had an episode. We attached the resuscitator to GRO-B and to the oxygen. He normally responded to the resuscitator. We left the resuscitator on for 15 to 30 minutes I think, and he had a weak pulse and shallow breathing. As H was terminally ill, I knew that he could die at any time, but it was still a shock. As H was dying, my brother, and a carer were with him. I stayed with him too and prayed. I phoned the doctor who also came. H died quietly, with dignity, and with his family.

33. H 's death certificate showed: 1A cardiomyopathy and 1B GRO-B . A post mortem was not undertaken because H was classified as terminally ill. Before that, H had been given six months to live at 30 years old due to the condition of his heart. However, with my expert care he was able to live much longer than expected. I gave up my life to care for H

Section 3: Other Infections

34. As far as I am aware, H did not have Hepatitis B at any point. I am also not aware that H contracted any other infections.

Section 4: Consent

35. Unfortunately, I still do not know when or how H was diagnosed with Hepatitis C. I have assumed that they picked it up from routine blood tests that they were undertaking. Again, I need his medical records to clarify this.

Section 5: Impact

Impact on H

36. H attitude was that no matter what was wrong, he wanted to know about it. Following the diagnosis with Hepatitis C H was suicidal. I believe it was the straw that broke the camel's back, between the cardiomyopathy and the fact that

his body was nearly paralysed due to his GRO-B. Psychologically, it was too much for him to deal with at the time.

37. In 2000, after being diagnosed as terminally ill, H was told he needed a pacemaker in his heart and he would not have the surgery, due to his Hepatitis C and haemophilia. H cried about that and said he was too poorly for the surgery, because *"he was filled with dirt and filth from people in America."* I believe H had seen this on the news and this was what he believed. He believed that prostitutes and prisoners had sold their blood cheaply in the United States and that was the blood H had been given.

38. H was a very brave person and he was able to tolerate very high levels of pain. Between myself and our two children, we kept him feeling safe. However, despite this, some times were bleak and he would have depression.

39. On a couple of occasions, H went into a hospice in GRO-B for respite care and I did tell them that his blood was "funny". At times he had spontaneous rectal bleeding and I told them his blood was thin and watery. I also told them that he had Hepatitis C, although they would already have known this from his medical notes.

40. H was able to come to terms with his diagnosis because of his faith. A priest in GRO-B journeyed with him. That priest was a saint, he came to sit with him and so H diagnosis with Hepatitis C clearly did not bother him.

Impact on me

41. After I found out that H had contracted Hepatitis C, I started wondering whether the District Nurses caring for H in GRO-B knew about his infection before we did. One of those District Nurses was my friend. I felt as though the nurses and doctors were making decisions for us.

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42. The impact on me of H diagnosis and death has been significant. Following H diagnosis we had no intimacy in our marriage, as he did not want to infect me. I also did not want to be infected and this was a big strain on our marriage.

43. After H died, I was just broken. I have spent a lot of money over the last few years for specialist therapy for post-traumatic stress. I did not feel right and I sought help.

44. At around 30 years old, I realised my prayers were not going to be answered and H was not going to walk or work again. I did turn to drink for a while then. I went to Alcoholics Anonymous ("AA") and I had eight years sobriety when H died which continues now. H death could have pushed me back but I spoke to my sponsor and went to AA. I did want to drink myself to death but I stayed firm in my decision not to drink.

Impact on family life

45. The children were also bullied at school but mainly because their father could not walk and was disabled rather than it being because of the Hepatitis C infection, as we were not aware of this at the time. The children knew their father had GRO-B and haemophilia. The children did not tell me until after they had left school that they were being bullied. At the time I was trying to do everything between working, caring for H and the children. GRO-B told me he did not want to worry me by telling me about the bullying. I believe that the school had a word with the child bullying him at the time.

46. Both of our children, GRO-B and GRO-B, saw their father have minor cardiac arrests at home, which must have affected them. We did not find out that H had Hepatitis C until the children were 24 and 23 years old respectively. We told our children about H diagnosis when we found out in GRO-B.

47. When H was 39 years old, GRO-B was in a car accident. He had multiple fractures and ended up in a wheelchair for a while. Both H and GRO-B were

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in wheelchairs at the time. GRO-B was 29 years old when H died, and turned to drugs and drink to cope. He is receiving treatment and he is recovering now.

48. GRO-B and GRO-B left school and did not go to university. I believe this was because they were too broken from their journey with their father.

49. GRO-B got 10 GCSEs and worked in the music store HMV. I believe this was because she felt she needed to stay at home at the time. She moved to GRO-B before we did; we moved there because she wanted us to live near her so that she could help to support her father, which she did on a daily basis. GRO-B was 28 years old when her father died. She partially completed a maths degree and now runs her own business with her husband.

50. GRO-B was always very stoic and although she wanted to assist with this Inquiry, she found it too upsetting. She said she is not able to talk about it but she does want her father's voice to be heard. She wants to know the outcome of the Inquiry but she does not want to be involved with it. I have not asked GRO-B whether he wants to be involved, as I do not want to push his recovery back and put him at risk. H diagnosis and subsequent death has had a very significant effect on our whole family.

Impact on employment and finances

51. H stopped work at around 30 or 32 years of age. He was a GRO-B GRO-B but he had to stop working due to his illness, particularly with his heart. I do not know whether Hepatitis C exacerbated his existing heart condition; I do not even know if he had it at that time as no-one has told us the date he was infected.

52. As referred to above, I worked until I was 49 years old in order to ensure there was some income coming into the house. Then I received attendance allowance for H. DWP provided some assistance when I stopped working and until H died. Unfortunately, I was not allowed to be paid as a carer as I was H wife. We had to pay £20 a week for H carers, as this was not paid by the Council.

We were not given any grants or scholarships to assist with the children's education.

53. We were given a Motability car, which was a Godsend. We received a car when they first became available in the 1970's. As [redacted] deteriorated we were given vans with ramps, so that we could put [redacted] wheelchair in the back. They came to take the van away immediately after [redacted] death.

Difficulties and obstacles to treatment

54. We were not given any help. There was some limited respite care and the staff were okay, but other staff treated us as contagious and that made [redacted] upset. I had to keep him at home and nurse him myself.

55. I recall on one occasion [redacted] went into Queen Alexandra Hospital in Portsmouth with an issue with his heart. His pulse was 130bpm, which was high, and his breathing was erratic. The doctors told me there was nothing they could do. However, as a nurse, I was aware they could prescribe medication to slow his heart and stabilise him, and give him diuretics. The doctor told me that he did not need to do anything and he discharged [redacted]

56. I spoke with the GP, who recommended that I take [redacted] back to Queen Alexandra Hospital in Portsmouth. The Consultant came around with another doctor and I discussed with her [redacted] high pulse rate and condition. I asked her whether she was trying to euthanise [redacted]. Doctors are not used to patients being so forthright.

57. In the end, the doctors did treat him with intravenous diuretics and digoxin. I did ring the nurses' office and made a complaint. The Nursing Officer then asked me for a meeting and asked whether they should refrain from giving [redacted] antibiotics if he had a chest infection and we both said no. [redacted] did not want to be resuscitated but he also did not want to be killed off before his time either.

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58. During the same admission, there was also an incident where I had asked for H drinks to be kept cold, even his tea, as he was having spasms and I was worried the jerky movement would lead to him being burnt. When I mentioned this to a nurse, she put her hands in a jug of ice and threw ice cubes in his tea which made it cold rather than cooling it a little as I had asked. I did put in a complaint following this behaviour, however, I did not take it any further than that. The nurses were clearly having difficulties with basic care. I mentioned it to Dr Green, a consultant on the ward, and he said he would have a word with the nurses. H was stressed and so I decided it would be best to take him home.

59. Another example of difficulties with treatment during that admission was that H was hungry, so he was brought food on a trolley, but he could not reach it. At home he needed feeding and so he needed the same care in hospital. I was not given a reason for the nurses not wanting to feed H Unfortunately, H would never have complained about how he was treated in the Queen Alexandra Hospital in Portsmouth.

60. On a separate occasion, I cannot recall when although it was in hospital in Portsmouth, I had to take him for an endoscopy for a rectal bleed. I was told we needed to be left until last. At the time they knew H had Hepatitis C and our appointment was first in the day. I asked them why this was but they did not answer me. By then I was so tired and worn out with it I did not dispute this.

Stigma

61. I did feel there was a stigma attached to the diagnosis. This was particularly apparent in the Queen Alexandra Hospital in Portsmouth. Some nurses did want to deal with us and some did not. Our friends were okay with the diagnosis. We never had any support from H sisters but fortunately I had a big family in GRO-B who were very supportive.

62. There was a stigma at the church. During the late 1980's we had seen reference to Hepatitis C on the news. I recall one incident when my daughter was around eight years old and she was at church, a woman said to somebody "*keep away*

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from her, you could catch something." Fortunately, my daughter was a strong character and she replied "*that's a nice way to talk in a church.*" We did not know about H diagnosis with Hepatitis C at the time, and so the woman must have been making an assumption.

Section 6: Treatment/ Care and Support

63. Generally H was treated at the haemophilia centre at Walsgrave in Coventry. He was under the care of a Consultant in Coventry for haemophilia, Dr GRO-D GRO-D, and he was under the care of a specialist in GRO-B in London and then a Consultant Neurologist in Coventry.

64. We were never offered any counselling by any of the three hospitals we attended in Coventry, London or Portsmouth. I feel this would have been helpful for me and my children.

Section 7: Financial Assistance

65. In terms of financial assistance, I have not received anything. Unfortunately, H died a year before financial assistance was awarded to infected haemophiliacs. We did not apply for any financial assistance from the Skipton Fund or EIBSS, as I did not know about it and I am not sure whether I would have been eligible. I may now ask for assistance from The Haemophilia Society or the haemophilia nurse that cared for H to see whether I am entitled to any financial assistance.

Section 8: Other

66. I would like to give my evidence to the Inquiry anonymously because I feel that over the years my children have been stigmatised enough already. I would not want to risk their current positions.

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67. I would like the Inquiry to hold somebody accountable. The law of the land is that euthanasia is illegal. Family assisted suicide can result in a 14 years prison sentence. If the government knew that the Factor VIII they were importing was contaminated, who is responsible for the murder and mass genocide of haemophiliacs? Why was this allowed? I believe those are key questions the Inquiry should seek to answer.

Statement of Truth

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

Signed ...GRO-B.........................

Dated..........29.10.2019..................................