Witness Name: Susan GRO-B
Statement No: WITN1267001
Exhibits:WITN1267002-8
Dated: December 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SUSAN GRO-B

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

Section 1. Introduction

1. My name is Susan GRO-B, DOB GRO-C 1957 and I live at GRO-C, GRO-C Liverpool GRO-C. I am currently unemployed and living with my partner, and I am the mother of three sons, all of whom had haemophilia.

2. My first son, Brian GRO-B (DOB GRO-B 1977), died on GRO-B 1994 after being infected with HIV and Hepatitis C through contaminated blood products.

3. My second son, Stephen GRO-B (DOB GRO-B 1980), died on GRO-B 1989 after also being infected with HIV and Hepatitis C through contaminated blood products.

4. My third son, GRO-B: S (DOB GRO-B 1984), was infected with Hepatitis C through contaminated blood products.

5. This witness statement has been prepared without the benefit of access to my sons' full medical records.

Section 2. How Affected

6. Brian was a moderate haemophiliac (clotting factor of less than 3%); Stephen was a severe haemophiliac (clotting factor of less than 1%) and S suffers from severe haemophilia (clotting factor of less than 1%), all type A. They were all treated with Factor VIII concentrates at the Alder Hey Children's Hospital under Dr Martin (Consultant Paediatrician) and Lynne Ball (Consultant Haematologist), Dr Bolton-Maggs took over from Lynne Ball. There was a history in the family of haemophilia so it didn't come as a surprise when they were diagnosed.

7. When S reached the age of 17 his care was transferred to the Royal Hospital, Liverpool.

8. I believe the boys always received Factor VIII. We were not told anything about Factor VIII and we received no advice whatsoever. I didn't know where it was coming from. I thought it was something that was going to help them and it appeared to be better treatment than what my brother had received (he also suffered from haemophilia).

9. A copy of Brian's treatment record is now shown to me marked **WITN1267002**. This shows that he had Lister, BPL and Armour products.

10. A copy of Stephen's treatment record is now shown to me marked **WITN1267003.** This shows that he was also treated with Lister, BPL, Armour and Cutter products.

11. We were told that the boys needed to go for blood tests. I never even thought to ask what the tests were for as it was just the norm as they were haemophiliacs; they were always having blood taken.

12. We later received a letter which said that Brian and Stephen had been infected with HIV. My dad saw my extreme reaction to the letter and came over to ask what was wrong. He took the letter off me as I was about to faint and sat me down on the couch. He went out and got the family doctor and showed him the letter, which I have not seen again since. I find it disgusting that I was informed of my sons' HIV status by a letter; something that the Government has repeatedly denied.

13. We were asked to go to Alder Hey the following week. Dr Martin was standing there and he said 'I don't want you all coming up here with coughs and colds'. He basically told us that if

they had symptoms he didn't want us to bring them to the hospital as not all symptoms were a result of HIV. I was not provided with any information about the virus itself and I was given no information as to the possible routes of transmission or risk of infection to others.

14. Concerns were raised about Stephen's health in October 1984. His clinic notes dated 18 October 1984 confirm he had a full blood count taken and that liver function tests and tests for Australia Antigen were planned.

15. Stephen was first given heat treated Factor VIII on 7 May 1985.

16. Stephen had blood taken for HTVL III screening 8 August 1985 (as referred to in his clinic notes). There is correspondence in Stephen's records that confirms he tested positive for the HIV virus in October 1985. There is reference to him being antibody positive and "?AIDS" on 2 April 1986. However, the first reference I can find in his notes to positive result is the clinic note dated 9 March 1987. Copies of these documents are exhibited at **WITN1267004.**

17. Stephen had pneumonia in October 1987, a bronchoscopy in the December. On 29 January 1988 he was recorded as having AIDS related complex with very few T4 helper cells.

18. There were serious discussions regarding AIDS in 1988. Stephen was put on IV pentaminde in June 1988 and there was a note made in his records to say only medical staff could take blood because he was HIV positive. His LFTs were being monitored regularly. He had peripheral neuropathy in November 1988.

19. Stephen was notified as a possible case of AIDS related illness on 21 January 1988. On that form his current status was recorded as positive with the date of sample given as 22 October 1987 and the date of his first positive sample was recorded as 8 August 1985. A copy of this form is now shown to me marked **WITN1267005.**

20. There is now shown to me marked **WITN1267006** a letter which confirms that Brian was diagnosed as being HIV sero positive when he was first tested in 1985.

21. His blood tests were marked Biohazard 3 because of his HIV status and were also stamped "Danger of infection".

22. Fortunately, S did not have HIV. I remember Brian being happy for his brother that he hadn't also been infected.

23. I was kept in the dark when my sons were first infected and I absolutely should have been told earlier than I was.

24. I do not recall being told Brian had hepatitis but I note that there is reference to this in his records as early as 13 June 1988.

25. I do not believe that either Brian or Stephen's records are complete as I have been unable to locate a copy of the letter which first informed me of their infections and I believe that there are test results missing. My partner has reviewed the medical records in detail and is convinced that they are not complete. For example, there are no references (at the time) of when my sons were diagnosed with HIV, yet notes two years later which refer to these dates.

26. Furthermore, there are only two lines on the date that Stephen died, at the bottom of a page, and as these ended mid sentence, it is clear there were further notes, but the next page is missing.

27. Stephen died in May and it was GRO-Bth birthday in the GRO-B. We had been planning for months that we would go to quasar with all of his friends. As I didn't want to upset S I had to go and watch all of these kids enjoy themselves a month after my son died.

28. In 1997 I was called to the hospital and went with my partner Dave where they told us that S had tested positive for Hepatitis C antibodies.

Section 3. Other Infections

29. I note from his medical records that Brian also tested positive for EBV and CMV in 1990 and 1991. There is now shown to me marked **WITN1267007** a copy of his test results. Stephen was also tested for these as early as 1987. Reference to this is now shown to me marked **WITN1267008.**

Section 4. Consent.

30. I didn't have knowledge of any testing that was carried out on my sons and as such I could not have consented to these tests.

Section 5. Impact

31. The boys' school was just around the corner from us and they would often be brought home with bleeds which meant that I couldn't work as I had to stay at home for them. The effect on my sons' education due to the effects of AIDS would have been dreadful if they had lived until adulthood because of the amount of schooling they missed, so much so that Brian had to be home schooled by a tutor to help him keep up.

32. Our lives were effectively put on hold and we merely existed, trying to cope as best we could. We spent most of our time at Alder Hey Hospital and our social life was non-existent. The constant visits and stays in hospital took its toll not only on Brian and Stephen, but on me and S also. I cannot put into words the dreadful strain on my family.

33. There was such a strong stigma surrounding the virus that when I would take Stephen out in his wheelchair I would tell people that he had leukaemia. We had heard of a little boy in America who had been infected with the HIV virus and his family had been hounded and harassed, so we were wary not to tell people.

34. Even some people who were supposed to be medically trained had a dreadful attitude, such as a doctor who put gloves on when he was only talking to my sons and the bank nurse who questioned other nurses about the fact they were drinking out of cups that my sons had previously used. The regular staff however were brilliant.

35. The people on our street threw a party to raise money for the boys as Stephen was losing a lot of weight and was visibly ill, although people didn't know that he suffered from HIV. Streets all around us were getting involved and raising money for Stephen which was really special to see.

36. Social Services were asked if we could have a slope made at the front of the house to make it easier to get a car and wheelchair up and down. I was asked if it would be worth it 'as Stephen will probably be dead soon'. I was absolutely astonished that someone could say something like that.

37. Stephen's medical notes say that he became aggressive and said "leave me alone, I am going to die, what more do you want? I do not believe that Stephen was ever aggressive, He was just angry that he had to attend hospital all of the time.

38. Stephen was treated with AZT from 1988. He suffered terribly from a vary bad cough, tonsillitis, earaches, vomiting and chest infections. He became skeletal. The only time I had seen children like this was on the television from abroad; children who were just skin and bone. This happened to Stephen as he couldn't keep down any food. I had to give him drumstick lollipops so he had a nice taste in his mouth; that was all he had.

39. The Wish Foundation had arranged a trip to Disneyworld and the boys were so exited that they were marking the days off the calendar, but their excitement came to a sudden end as America would not give us a Visa as my sons had HIV. After Stephen's death I was eventually able to take Brian and **S** to Disneyworld, but even then the airport security made comments about all the treatment we were bringing through for the boys. I was confronted by an armed security guard over this.

40. For several weeks Stephen had a terrible cough, and as his mother I just knew that it was serious. I took him to Alder Hey several times but was told by the consultant that there was nothing wrong with him. As the cough got worse, we went back to the hospital and were seen by the consultant and another doctor. The doctor took me into a side room and told me that I was an over anxious mum. He ignored my pleas and sent us home. The cough continued to worsen and so I took him to A & E. They took an X-ray and told me that his lungs were badly damaged. They rushed him to an isolation ward where I was told that he had pneumocystis.

41. Stephen was put on Morphine which was terrible to see. He died at home in 1989 following the pneumocystis infection. When he died I kept him in my arms and wouldn't let him go. I couldn't come to terms with the fact he had passed away. I just couldn't understand it. I was told my one of the nurses that came round afterwards that we would have to take him to the funeral directors. I screamed at them and said "you had better bring him back here, otherwise I will break in and get him myself". They knew I was in a bad state of mind, and I would have done it. When they brought Stephen back the coffin lid was nailed shut. The last time I got to see my son was when they took him from my house to the funeral directors.

43. Lynn Ball said that the death certificate should read Bronchial Pneumonia secondary to the deficiency virus relating top haemophilia. This is wrong – it should have made reference to AIDS. In Brian's records there was a note to say "his brother died of AIDS".

44. Brian used to suffer from crippling headaches for which he required Pethidine injections. One day S wanted to go to his friend's house. It was only 5 minutes drive away and Brian said he would be alright at home, so I dropped S off and came back. When I returned, I checked and found that Brian had given himself a further Pethidine injection because his headache was so bad.

45. Brian's condition made him very depressed and when his headaches got so bad, and following a particularly painful enema, he said he wanted to throw himself out of the window.

46. The following week they sent round a social worker specialising in drug addiction. I was shocked. She said she was there because Brian had taken an overdose, and wouldn't accept the fact that he was just trying to stop his crippling headache.

47. Brian was put on all the drugs that came out, and he would have side-effects with each one of them. There was one drug in particular that was really bad and caused terrible sickness and diarrhoea. In the end he just had to be treated with AZT.

48. Because of his AIDS, as well as his crippling headaches, Brian suffered from shingles, terrible constipation which required repeated enemas, tonsillitis and quinsy, low platelets. pancreatitis and swollen lymph nodes. He also suffered from deafness which required the fitting of grommets. He also suffered from epilepsy which resulted in grand mal seizures.

49. Brian was put on steroids and his weight ballooned – it was the opposite of what had happened to Stephen ehich again made him very depressed.

50. Towards the end Brian didn't want to go to hospital, so I kept him at home and we would be visited by nurses. Brian then went into a coma a week before he died.

51. One day S got into bed with Brian and wrapped his arms around him, thinking he was still in a coma. In fact Brian had died.

52. Brian had an open coffin, and people could come and say their goodbyes.

53. When I talk to S about his brothers he seems to close up. Brian was like a father figure to S and I know it really hurts him but he doesn't talk about it.

54. The financial implications were huge and dogged me for many years afterwards. Whilst Brain and Steve were alive I was totally unable to work. I had to borrow money off my dad for a portable heater because the house was so cold and we were struggling; we had no money. After they died the psychological damage made working extremely difficult. In fact things got so bad I tried to overdose as all I wanted was to be with my boys again.

Section 6. Treatment/Care/Support

55. We were not offered any help or support when the boys were diagnosed.

56. I wasn't offered any counselling. I was put onto Prozac just after Brian died and I am still on them now.

57. I went to see a psychiatrist after I tried to take an overdose. I had drunk a bottle of gin and reached into a medicine drawer that contained both Paracetamol and Ibuprofen. By pure chance I took out the Ibuprofen. I have been told that if I had taken out the Paracetamol I would have died. I was really struggling to cope after I lost the boys. I had mad moments and acted like an animal.

58. We had always been treated on the leukaemia ward; my brother had been treated there and the boys were treated there too. The nurses knew the boys well as they had treated them since the boys were babies, and the boys felt comfortable around them. One day after Stephen's death when we arrived at the hospital, they didn't let us go to our usual ward and eventually demanded that we be treated in the general ward instead.

59. There was a gate on the general ward to stop the young children from leaving, however the other children would play with the gate and keep slamming it shut, causing a loud noise. Brian was suffering with terrible migraines at the time and it was making things unbearable for him. I was very angry that they moved the boys' out of the ward where they were comfortable and familiar with the nurses. This was a cancer ward and was very quiet.

60. One day we had to take Brian to the hospital as he had an ankle bleed. When the doctor went to treat him, he said 'so where do we put the needle?' I laughed as I thought he was joking, but then he said he was being serious as he had never treated a haemophilia bleed before. I rushed and found Lynn Ball to tell her what had happened and to ask her to treat Brian, but she told me that she had been instructed not to treat HIV/AIDS patients anymore. Fortunately, she eventually treated Brian that day but I don't understand why she was told to not treat us anymore.

61. The staff who knew Brian and Stephen were excellent but I believe some of the problems we experienced were due to the stigma attached to HIV.

Section 7. Financial Assistance

62. Over the years I did receive payments but I cannot recall actual dates or amounts. I know that I received payments because my sons were infected with HIV and Hepatitis C.

63. When I received the first payments I was still recovering from Stephen's death. I received a phone call to say that I would be receiving a document that I would have to sign if I wanted to receive some money and that the sum offered was all that I would be getting. I was also told that if I didn't sign I wouldn't get anything.

64. The MacFarlane Trust provided us with a second hand stair lift for Brian. However, within days of Brian passing away they came to our house to take the stair lift back.

65. Several years ago I also received a grant to replace my kitchen and bathroom and the outstanding balance on some credit cards were paid off.

66. I also received funds to fix a plinth fitted to my son's grave and to repair the weather damage to the gold lettering.

67. The MacFarlane Trust paid for two lots of counselling for me. I would like to go for more counselling but I don't want to ask them for more, as any time I asked for anything it felt like I had to beg for it.

68. With regards to applying for assistance, I have always found this very difficult. I was made to feel that I was begging and had to "jump through hoops" to get the money. This included providing details of my income, expenditure, phone calls etc.

Section 8. Other Issues

69. We have been denied justice for many years and even today we are being lied to and misled.

70. After a long battle and several delays I eventually received my sons' medical records. The delay was not the fault of the staff member I was in touch with but I believe someone higher up the chain delayed the process.

71. I relive it all everyday; it never leaves you. Their birthdays are especially horrible every year. Brian loved art and Stephen was really good at maths. They wanted to do so much with their lives but were robbed of the opportunity to do so. When S and I went to London to the Inquiry it felt like I couldn't breath. We have waited so long for justice.

72. At Alder Hey Hospital it was like a conveyer belt of children dying. We would constantly get phone calls from other parents and families telling us that another child had died. The adults who were infected would not be aware of this because they were in a different hospital. I do not feel that the infected children are having their say and it has to be known what happened to the.

Anonymity, disclosure and redaction

73. I do not want to be anonymous.

74. I would like to give evidence to the Inquiry as I believe it needs to hear what happened to the children at Alde Hey Hospital but I am not sure that I would be able to cope with the stress of doing so.

Statement of Truth

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

Signed.. GRO-C ...

Dated........3/1/20........................