ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN3116001

Exhibits: WITN3116002 – WITN3116003

Dated: 1ST November 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. My date of birth is GRO-B and I live at The GRO-B. I am a retired nurse, having first started my nursing training in Birmingham in 1962, before becoming a staff nurse and a ward sister at the GRO-B Hospital GRO-B. I really loved nursing, before retiring in 1971.

2. I met my late husband, GRO-B, at GRO-B shortly after he was appointed as the GRO-B GRO-B there in 1967. GRO-B became the GRO-B GRO-B in GRO-B in 1969. The post covered all of Shropshire and Mid-Wales. We married in 1971 and I subsequently moved to GRO-B

3. I am an obligate carrier of haemophilia A. My grandfather had haemophilia A, but I assume it was mild because I do not recall him having any issues. My mother was an obligate carrier like me and had five unmarried sisters (with no children). I have a brother who has severe haemophilia A and two sisters who are not carriers of haemophilia.

4. My son GRO-B: S contracted HIV through being given contaminated blood products by the NHS. Sadly, S died in 1995 as a result of AIDS. I also only recently found out in October 2018 that I had contracted Hepatitis C through contaminated blood products, but it was asymptomatic. Whilst I discuss this further below, I am mainly providing this statement to the Inquiry to discuss the impact of S having contracted HIV through receiving contaminated blood products. I make this statement from my recollection of events, as I have not yet received S medical records.

Section 2: How Affected

5. GRO-B and I had two sons together. My first born son GRO-B was born in 1971 and does not have haemophilia. My second son S was born in 1973. He was diagnosed with severe haemophilia A, with less than 1% clotting factor, at around six months old.

6. S haemophilia was not a problem for us, given that he was born into a medical family. I do not recall him suffering from too many bleeds as a toddler. As a family we decided only to tell those who needed to know about S haemophilia, as we considered it a private matter. When S went to school, they were aware of his haemophilia. He was not limited at school through his haemophilia, but I used to attend school with S on Wednesdays whilst S had gym class, as a form of reassurance for the school.

Treatment

7. S did suffer from spontaneous bleeds every one or two months, but this was never an issue for us. Initially, we would need to take S to hospital for treatment. I am aware that S received Cryoprecipitate in 1976 to 1977 at the Children's Ward of The Royal Shrewsbury Hospital, probably as a result of joint bleeds.

8. I cannot recall exactly when S moved onto home treatment with Factor VIII, but I kept a record of the batch numbers for his home treatment which goes back to July 1977. I cannot recall any discussions about any risks with Factor VIII when S first started the treatment. I remember a conversation with GRO-B my husband, about a new product which would make things easier in respect of S treatment for haemophilia. I assumed GRO-B found out about this at work at the hospital. I was aware that it had to be stored in a fridge. My notes also record batches of Factor VIII manufactured by Armour (in the United States of America) being administered to S between 1980 to 1983 and 1985 to 1986.

9. Other than the Cryoprecipitate and the home treatment with Factor VIII mentioned above, S was also given Factor VIII in the Royal Shrewsbury Hospital as a result of a circumcision operation in 1981 and again in 1989 following some dental work. I remember S was bleeding a lot following the surgery and that he required a lot of Factor VIII both in hospital and post-operatively at home to stop the bleeding

10. In December 1984, I recall GRO-B telling me about an issue with Factor VIII, particularly with the product coming from the United States of America and a risk of contracting HIV. I assume he found this out at work at the Royal Shrewsbury Hospital. GRO-B said that S will have to be tested for the virus. I do not believe S was aware of any risks with Factor VIII until this point.

11. S always wanted complete honesty and therefore GRO-B explained to him the anxiety within the medical profession about blood products and the need for him to be tested for HIV. S was subsequently tested for HIV on 20 December 1984 and, in March 1985, it was confirmed that he was HIV positive.

12. I recall S saying *"so those who save my life will also kill me"*. That is all he said upon receiving the news. At the time I did not know much about HIV other

than people being terrified by it and that there was a lot about it in the press. The media attention was centred on the lifestyle choices of those who had contracted the virus, including homosexuals.

13. I remember discussing the HIV with my husband. I asked him whether S was going to die and he responded by saying possibly, but possibly not.

14. S was 11 years old when he found out he was HIV positive in 1985. . He was at preparatory school at the time. S was very intellectual and was even catching up to his brother with his studies at school. HIV was a very difficult subject to bring up and we chose not to tell his preparatory school, as we understood there was no risk of transmitting the virus to staff or other children unless he had a bleed. After preparatory school, S followed in his brother's footsteps to GRO-B School. When S moved to GRO-B School, the school doctor knew about his HIV and said that the only person who needed to know was S housemaster.

15. I decided only to tell people I really trusted about S HIV. These were only my closest friends. I believed there was so much prejudice in the public and I was constantly seeing so much anger and fear about HIV in the media and local community. For example, I remember at my local church there was a lot of fear and discussions about the sharing of wine for communion and the potential risk of transmitting HIV, given the media focus on HIV at the time.

16. S seemed to manage with the virus well at first and did well academically at school. He was also GRO-B for the school's GRO-B team and took part in other extra-curricular activities such as sculling. S was shorter in stature, about five foot nine inches, compared to his older brother, GRO-B who is six foot four inches and who was a GRO-B.

17. In 1989, when S was about 16 years old, I remember he spent a lot of the Christmas holidays being tired and sleeping a lot more than usual. This was out

of character for him. GRO-B thought that it might have been as a result of a surge in the HIV virus. Apart from this incident, he seemed fine otherwise.

18. S had wanted to be a doctor since about the age of four, like his father. However, when he was around 16 years old, there was a lot of publicity about a doctor who had contracted HIV and had to give up his profession. I remember thinking I would have to have a difficult conversation with S about this. However, when I went to discuss it with S he was already aware and knew immediately what I was coming to talk to him about. He was so intuitive like that.

19. Despite accepting that he would have to give up on his dream of studying medicine at university and becoming a doctor, S was determined to continue studying biology at school. At this time, studies tended to be categorised by the profession the student were likely to pursue, specifically either arts or sciences. Even though S was unable to pursue his dream of becoming a doctor, he said *"the school can think again if they think I am giving up biology."*

20. I remember having a conversation with his school and he was able to continue studying biology, together with French and German. GRO-B went to university first and studied biological sciences at GRO-B University. S followed his brother to GRO-B University in 1991 and studied German and Linguistics. He was also a cox of the GRO-B University rowing club.

21. In S second year at university, in around 1992 or 1993, he had the flu and this seemed to really take a lot of his energy. His health seemed to deteriorate from this point onwards.

22. S carried on at university and went to Germany on a placement year in 1993 to teach in a school in GRO-B. His accommodation was in a GRO-B where he met two girls called GRO-B They used to work at GRO-B where S was staying and they became really close friends with S. They also introduced him to other people, such as

GRO-B brother GRO-B, who also became close to S S really enjoyed his time in Germany and went to Oktoberfest whilst over there.

23. Whilst at Oktoberfest S suffered a head injury after being catapulted from a bench, when everyone who was standing on it jumped off. As a result, S had to have stitches in his head. This was the first time he told his German friends that he was a haemophiliac. I remember S telling us that when he went to the clinic they recommended keeping the stitches in. GRO-B and I thought this was unsafe, given that stitches should be removed after around five days. We told S to come home so that we could take out the stitches.

24. S remained good friends with everyone he met in Germany. When he came home, his health really started deteriorating. His chest was really not good, he had lost a lot of weight and he developed peripheral neuropathy, particularly in his feet which led to problems walking.

25. S went back to GRO-B University for his fourth year, but his health worsened quickly. On 3 December 1994 we received a call from S after he had been coughing up blood. GRO-B spoke to him and said he should pack up his stuff at university and come home. Fortunately, a friend from GRO-B was visiting S at university at the time and was able to help him pack to come home.

26. Two days after S arrived back in GRO-B he went to the Royal Shrewsbury Hospital. GRO-B was told that S might only have around 10 days to live. I was not prepared to accept this and said to GRO-B *"my son will not die in 10 days"*. We had almost 12 months with S after this date.

27. Whilst S had kept his HIV diagnosis private, he decided to tell all of his friends at this time, given the seriousness of the prognosis. All of his friends were amazing, particularly his six closest friends from GRO-B School. Whilst S kept his condition private up until this, we had discussed sexual

transmission of HIV with S. He never put any girls at risk. but still had so many close female friends.

28. S was loved by his friends. Many still keep in touch. He was always concerned about their welfare and had no self-pity for his own state of health. S had not been told he might only have 10 days left to live but knew he had become much worse. It was at this point that I said I would look after him at home, and we would face whatever happened in that way. He was obviously relieved and said that he did not want "to fester" on a ward with other very sick people. It was the right decision for us all. S received excellent care from consultants at home whenever a problem arose.

29. GRO-B was on a nine-month trip around the world at the time. He used to call every time he would get the opportunity to check in on S After being told S only had 10 days to live, we told GRO-B to come back home. S also spoke to him and said *"I am really sorry, but I need you back"*. They were really close and GRO-B came home to see his brother. S promised GRO-B he would pay for GRO-B to go back on his trip once he was better.

30. Our local GP, GRO-B lived just up the road which was also useful. Dr GRO-B came to the house every morning during the last three months of S life, before going to the surgery for his morning clinic. He was the perfect GP for S. They had a very good relationship.

31. I remember a conversation with S in his final months where he was just lying in bed contemplating. I asked whether he was worrying about death and he said no he was getting things sorted in his head. He was like that and just faced everything that came in front of him. S was a strong character.

32. S continued to deteriorate and had to have a wheelchair because he was unable to walk. He had a strong Christian faith and would have private conversations with the Reverend GRO-B before his death. Whilst I was not privy to those conversations, Reverend GRO-B later told me

that S asked him to *"look after my mother when I die, my brother and father too, but mainly my mother as she will need you".*

33. I slept in S bedroom for the last three months of his life. I remember the last 24 hours being particularly bad. We did not get much sleep that night and in the morning he said to me *"I suspect if I have another night like that you will have to call the undertakers".* I reminded him that he told me previously he expected to be with us for Christmas, but S said he did not think so anymore.

34. On GRO-B 1995 I remember him receiving three letters from friends. I went upstairs and passed these to him so he could read them. S had vomited into a sick bowl. I called GRO-B into S room and I told him to wait there whilst I went and emptied the sick bowl downstairs. When I went downstairs, S died. It really caught me unexpectedly. It was really difficult.

35. Shortly after S died, one of his friends, GRO-B arrived at the house. He was working with GRO-B at the time. He stayed and rang round S close friends to inform them of his death.

36. S death certificate lists the cause of death as:

1a. Acquired immunodeficiency syndrome;
1b. Haemophilia (contaminated blood products).

37. Reverend GRO-B prepared the eulogy for S and I have exhibited his kind words to this witness statement [WITN3116002].

Section 3: Other Infections

38. I do not believe S contracted any other virus as a result of contaminated blood products. I also do not believe he was tested for Hepatitis C.

Section 4: Consent

39. Given GRO-B role as a Consultant Paediatrician, I assume he probably had a conversation with the haematologist, which then led to GRO-B telling S, who was only 11 years old at the time, that he would be tested for HIV. I do not believe there were any issues of S being tested or treated without our consent.

Section 5: Impact

Stigma

40. S did not suffer any issues with his treatment and we did not personally feel the impact of any of the stigma around HIV at the time. As mentioned above, we generally kept S condition private, as we believed it did not concern anyone else. The stigma might have played a small part in our decision to keep it a private matter, but ultimately it was a private matter as far as we were concerned.

41. When S died, we put a notice in the local paper and The Times and asked for a donation to the local Haemophilia Centre. We did not receive any stigma as a result of this either.

Impact on our social life

42. The diagnosis had little impact on S social life. He had such a good group of friends and even during his last 12 months, the socialising just moved to being held at our house.

43. S had become very gaunt and thin. He also had a strain of Tuberculosis which HIV patients were vulnerable to. He received treatment for the Tuberculosis, although I cannot recall the name of the treatment. There was one occasion when it took me one and a half hours to get S ready to go to a 21st birthday party. It was a formal party and S wore a dinner jacket. He

was determined to attend this party, as his friend wanted him there so much. S managed about two hours at the party before he got exhausted and had to go home. His friend was so pleased that S managed to attend even for a short while.

44. S and I did not experience much of an impact on our social life either. I had a sister living close to us in GRO-B so if we wanted a night out at the theatre, she would be able to look after S whilst we went out. S liked that we had our own routine with his care and that we were also able to do other things.

Impact on the family

45. As a trained nurse, I immediately understood the implications when S was diagnosed and thought about them a lot. We just had to carry on with life and, to begin with, S life was good and he appeared to be managing with the HIV virus.

46. When S health started deteriorating it bothered me a lot more, but S coped so well and was so strong that I had to do the same for him. It was still very distressing to see him physically deteriorate and I would like the Inquiry to see some photographs I have selected of S [WITN3116003]. The photographs show his physical deterioration between the period of 1992 and 1995, with the last photograph being taken three months before he died. I want the Inquiry to be able to see my amazing son.

47. I began preparing myself psychologically for S death, particularly during his last 12 months when I was nursing him at home. When S died it was really devastating, despite how well I thought I had prepared myself. At his funeral, I did a reading called "Death Is Nothing at All". I remember practising the reading in secret for about three months before S death, in preparation, so that I could read it without crying. It was so strange because after the funeral, one of S friends told me S had mentioned he liked that reading

and had shown her it. This was when he was still at university. I had never spoken to S about it.

48. After S death I was determined not to be miserable or a maudlin mother, because I knew that was not what S would want. I struggled for a while and would say that it is not the big things that catch you, but the little things that still get me today.

49. GRO-B worked throughout S illness. He retired at the age of 62 in April 1995 as he had planned to do. GRO-B was very quiet about S death, but I knew he missed S a lot. They were both very intellectual and used to enjoy having discussions with one another. I have always been able to tell people that S was a haemophiliac and got HIV from contaminated blood products. GRO-B, however, struggled with this, even after S death, as he was a very private person. GRO-B died on GRO-B 2005, almost 10 years to the day after S GRO-B died eight weeks after a diagnosis of Alpha One Anti-trypsin disorder, which in his case was a primary liver tumour.

50. The loss of S has also been very difficult for GRO-B. He felt a big gap in his life following S death and said to me that he had nobody left for him in GRO-B I reminded him that this was not correct and he still has lots of friends in GRO-B

51. The most distressing thing I found about S death was that he had to go into a body bag because of his diagnosis of HIV. That was not a nice end, but I understand it was how it was done.

52. S lives on in my heart and will never ever go. GRO-B School have also named a GRO-B after S and when I go out walking I always keep an eye out just in case it GRO-B. It brings a smile to my face when I see his GRO-B.

Section 6: Treatment/Care/Support

53. We did not experience any issues with S treatment. In around the beginning of 1995, I recall an issue when S applied for 'Motability' and needed his doctor to sign the forms. The consultant at the Royal Shrewsbury Hospital refused to sign this form, saying S did not need a 'Motability' car at the time, despite him having peripheral neuropathy. This was completely ridiculous, but S was able to take the form to his GP, who signed it. It was only after S had died that this same consultant said to me '*S was really someone wasn't he"* and I just thought *"did it take his death to make you realise this?"*

54. S also never considered counselling probably because he was born into a medical family. I do recall there was something being offered in GRO-B at the time where you could have a "buddy" for counselling. This was alien to S, and he did not feel like he needed counselling. I also did not feel like I needed any counselling either.

55. If counselling had been offered to me I would have refused it. I dealt with the grief in my own way, for example. doing gardening, which I find therapeutic.

Section 7: Financial Assistance

56. In 1991 S received a settlement of £20,000 from the Macfarlane Trust. I remember he used the money to buy his own car, which helped him to travel to and from university in GRO-B.

57. I also remember receiving a £10,000 ex gratia payment from the Macfarlane Trust some time before S received the payment in 1991. Personally, I found the Macfarlane Trust to be very helpful and they were able to provide good advice over the telephone. S would contact them sometimes and get advice.

Section 8: Additional Information

My diagnosis with Hepatitis C

58. I had my gallbladder removed in 1979 and had to be given some Factor VIII for the operation, as I am a carrier of haemophilia. Following some routine blood tests in 2018, I recently found out that I had contracted Hepatitis C from that batch of Factor VIII, but it was asymptomatic. I was not offered any testing for Hepatitis C before this date.

59. I have never known about this before 2018 and therefore do not feel like it has had a great impact on me. It is likely I had Hepatitis C for 39 years without knowing it. Following the blood tests, I had the usual liver scans and fibro scans but my liver showed no signs of damage. I was given an eight-week treatment course of Harvoni medication to clear the virus. I remember being told that the potential side effects of the medication would be some headaches. I suffered from occasional headaches as a result of the medication and it "knocked me about" quite a lot.

60. My brother also contracted Hepatitis C from contaminated blood products but was also able to successfully clear the virus following a treatment course. He did not contract HIV.

Litigation

61. Wace Morgan solicitors contacted us about joining a class action litigation. GRO-B and I discussed this before deciding to go ahead with it. S also decided we should pursue this claim.

Conclusion

62. Overall I would like the Inquiry to be able to provide answers to me and the other families impacted by the contaminated blood scandal. It has pained me to learn

of the other families who were treated so badly and without compassion after they lost their loved ones at other hospitals around the country. As a former nurse it horrifies me. I think people are entitled to an apology and the truth.

Statement of Truth

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

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

Dated......1st NOVEMBER 2019.