Witness Name: GRO-B

Statement No: WITN1435001

Exhibits: 0

Dated: AUGUST 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. My date of birth is GRO-B 1952. My address is GRO-B GRO-B I am married with three adult children and five grandchildren. Both of my parents have now passed away.

2. I am a Haemophilia carrier, and Haemophilia has been part of my life for the entirety. My late father, Mr GRO-B: F F lived at GRO-B, GRO-B His date of birth is GRO-B 1920. F had severe haemophilia A and contracted the Hepatitis C Virus (HCV) through receiving contaminated blood products. He was also treated with infected blood products carrying the Human Immune Deficiency Virus (HIV), however this never developed into HIV because it was discovered that he had natural immunity to the virus.

3. My son GRO-B: S of GRO-B GRO-B also has severe Haemophilia A, and contracted Hepatitis C through receiving contaminated blood products for treatment of his Haemophilia. He is now married with two children. He is providing is own statement.

4. This witness statement has been prepared without the benefit of full access to my father's and son's medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Affected

5. Both my father and my son had severe Haemophilia A. They both received treatment of Factor VIII. According to my father's medical notes he received treatment with Factor 8, Immuno, EB VIII, Oxford FVIII, BPL FVIII 8Y, BPL FVIII 8SM, Recombinate and BPL FVIII 8Y2 between 1977 and 2001.

6. He had BPL FVIII 8Y for most of that time. I don't know what he had prior to 1977, and I don't know when he was given the infected treatment, or which batch numbers were the infected ones. Both my son and my father were treated at the Oxford Haemophilia Centre. Dr Rizza and Dr Matthews were the main doctors initially. Later it was Dr Giangrande. Lots of other doctors came and went over the years, but they were the main ones.

7. My father told me that Dr Matthews had told him, not to have any Factor VIII if he could possibly help it (my father didn't have treatment very often) because it came from the USA and came from people in prison, drug addicts etc. and that people were paid for donating their blood.

8. My father passed this information on to me because he was worried about his grandson having Factor VIII from this source, and the possible implications. However my father was a bit of a worrier and, because of that, I'm afraid I didn't take this information as seriously as I should have, I thought he was probably worrying unnecessarily. It wasn't that I didn't believe him but I thought "this is the NHS" they aren't going to give small children treatment that isn't safe, not in this day and age.

9. I didn't want my small son to suffer and be in pain. I was told by doctors that the pain from Haemophilia is one of the worst pains one can have. I didn't want my son to grow up with deformed limbs, unable to walk properly like my dad, but on the other hand I didn't want to risk his health, or risk him getting something worse.

10. I'm not exactly sure when this was, but my son was born GRO-B 1980, so it must have been sometime in the early 1980s. I don't remember anyone actually giving me any

information or telling me of the dangers involved at this time, other than what my dad had told me, so I'm afraid I put all my trust and faith in the NHS.

11. Later on I remember going to a meeting in a lecture room at the Churchill Hospital in Oxford, hosted by Dr Giangrande. I think it was primarily for parents of children with Haemophilia to talk about whether they should continue to use Factor from the USA. I don't remember exactly when it was but it was definitely before the summer of 1986, it may have been 1985.

12. During this meeting we were persuaded that continuing to obtain factor from the US was the best thing to do. Dr Giangrande told us that patients with Haemophilia were much more likely to die from their Haemophilia than from anything they were likely to get from the Factor VIII. This put things into perspective for me, I remember thinking to myself that I was right all along and dad was worrying unnecessarily. I was very much mistaken.

13. I believed what they told us, I was just a young mum, and they were eminent doctors; the natural thing to do is to believe what they were saying. Knowing what I know now, both my son and my dad could easily have died as a direct result of their treatment, along with all the others that have died.

14. To think that I either gave my son or allowed him to have something that would have killed him, just because I didn't listen to my dad; it doesn't bear thinking about, I would never ever have forgiven myself.

15. We only found out in 2009 that both my son and my dad had been treated with Factor VIII infected with HIV. This was long after my dad had passed away. We only found out because they wanted to send some of my son's blood to Germany to take part in a study to help find a cure for HIV, and apparently now they have to ask permission to do so.

16. Lara Oyesiku, the Clinical Nurse Specialist from the Oxford Haemophilia Centre, told my son, that both he and my dad had been treated with Factor VIII that had been infected with HIV, and neither of them had gone on to develop HIV, so they must have a natural immunity that only 1% of the white population has, which I believe is an absolute miracle, and I am so grateful for.

17. I remember being very worried because my son was unwell for a whole month back in September 1987 with a sore throat just after we came back off holiday. I took him to the Centre and told them my fears. I was worried in case he had HIV. I expected them to reassure me and tell me there was probably nothing to worry about, but they didn't; in fact they took it very seriously, which surprised me.

18. Knowing now that they knew he had been treated with HIV infected Factor VIII, I think maybe they knew then! Both my father and my son were also infected with Hepatitis C through receiving contaminated blood products. My father was also exposed to the Hepatitis B virus, and as a result developed a natural immunity according to his medical notes.

19. I don't know when my father was told about his Hepatitis C as he never talked about his Haemophilia or anything to do with it but my mother confirmed that he was Hepatitis C positive, and my father's medical notes confirm this too. I have found a letter to my father's GP from the Haemophilia Centre dated January 1998, mentioning that the implications of his Hepatitis C had been discussed with him. In the letter also states that my father claimed he had not been told of this before, although in his medical notes it says that he had.

20. I remember very clearly the day I was told that my son was Hepatitis C positive. I was told very bluntly by Dr Giangrande - he just blurted it out, with no preparation whatsoever. I can't remember exactly when it was, but I know it came as a huge shock, and it was just at a time when I thought we didn't have to worry anymore about the safety of Factor VIII.

21. I don't remember being given any information much, but that may have been because I was so shell shocked, and I was on my own; my husband wasn't with me, and I had no idea at the time what was going to come. It would have been so much better if my husband and I had been together and we had had some idea of what was coming, some preparation beforehand, instead of it coming straight out of the blue.

Section 3. Other Infections

22. My son and my father both received letters concerning nvCJD in 2001.Telling us that a blood donor in the UK who had donated plasma back in 1996, had recently been diagnosed as having nvCJD. Plasma from this donor was used by BPL to manufacture a number of blood products, including plasma-derived Factor 8.

23. The batches from this material were issued in 1997 and 1998. It went on to say that their records showed that both my son and my dad had been treated with some of the implicated batches. The worry went on and on.

24. I was quite surprised to read a paragraph at the bottom of this letter. It said "It is regrettable that the Department of Health did not follow the unanimous advice of the UK Haemophilia Centre Directors' Organisation (UKHCDO) and adopt the use of recombinant Factor VIII some years ago as this problem could have been avoided. It remains a matter of concern to us that recombinant Factor VIII and IX are still denied to most patients with Haemophilia in England, although these products are now available to all people with Haemophilia in Wales, Scotland and Northern Ireland."

Section 4. Consent.

25. We didn't know anything about Hepatitis C before we were told that my son had it, so he must have been tested without our knowledge or consent. We didn't know our son had been tested for HIV until we had the results, and by then he had been tested several times. I believe it was the same with my father.

Section 5. Impact

26. My father never talked about his Haemophilia, Hepatitis C or anything to do with it. My father was very ashamed of his Haemophilia, no one knew about it outside the family, any friends or neighbours, and we weren't allowed to tell anyone. He wouldn't have an ambulance to take him to hospital unless it was absolutely necessary, he would rather not go. So I don't know how it affected him mentally or physically. My son is writing his own statement.

27. We only found out in 2009 that both my son and my father had been treated with Factor 8 infected with HIV, long after my father's death. I am so glad that my father didn't know about it. He was so ashamed of his Haemophilia; he would have been absolutely mortified to know he had been treated with Factor VIII infected with HIV.

28. It was really difficult when my son was small coping with his Haemophilia, what with all the hospital visits. I think the record was five trips in one week for treatment, some in the middle

of the night, without having all the worry of what his treatment might be doing to him as well. As I said before I found it very difficult; as a parent all you want to do is to take the pain away and make things better for your child and I didn't want him to have to grow up with deformed limbs, in a wheelchair and unable to walk.

29. One of my first memories of the Haemophilia Centre when my son was a small child was of seeing a man in a wheelchair unable to walk with twisted legs, and I didn't want my son to end up like that. But then there is the thought that he could get something from the treatment, it's an awful worrying dilemma to know what to do.

30. Even though that threat did not seem that real to me in the beginning, it's always there in the back of your mind. I suppose when it boils down to it, the results of not having treatment were definite, inevitable, whereas the results of having the treatment were unknown at that time, a small risk, a possibility (and one which was played down or denied by his treating doctors). We didn't know the catastrophic nightmare that it was going to turn into.

31. I am just so grateful that although they both had Hepatitis C, they didn't get HIV. To think that both of them could have easily died as a direct result of their treatment for Haemophilia, like so many others have done doesn't bear thinking about, particularly as I treated my son at home from 1986 onwards and also treated my dad at home too for a while so I could have been the one that gave it to them. I don't think I would have ever forgiven myself. I don't know when my son and my father were infected with Hepatitis C or when they were treated with HIV infected factor because we were never told.

32. When my son was very small he used to scream the place down when he had treatment. It would take me and several other doctors and nurses to hold him down to allow the doctor to get the needle into his vein. Sometimes it took the doctor several goes to get it in and to think that on any one of those visits they could have been giving him Hepatitis C or HIV is just horrendous.

33. When my son was first diagnosed with Haemophilia we told friends and family that he had it and later on as he grew up we had to tell our neighbors, because he always had a leg or arm in plaster, or was in a wheelchair, otherwise they would have wondered what was going on. However, when it started to come out those people/children were being infected with HIV we stopped telling people and kept it secret.

34. I remember seeing on the news that a nine year old boy with Haemophilia had been infected with HIV and angry parents boycotted the school, and kept their children away from school. I couldn't cope with the possibility of that happening to my son so when my son changed schools, the headmaster and the teachers knew about his Haemophilia, but we asked them to keep it confidential because of the stigma associated with it.

35. Unfortunately, suddenly out of the blue, my son's teacher took it upon herself to single my son out and inform the whole class of his Haemophilia. My son was extremely upset and I was furious. I complained to the head, who was very sympathetic and apologetic, but the damage had been done. My father had always kept it a secret, I had always thought it was unnecessary up to then, but from then on I decided he was probably right to do so.

36. Regarding my father, my parents never discussed it with me so I don't know what impact it had on my mother. My father took early retirement, so I think he was probably already retired before he found out he was Hepatitis C positive.

Section 6. Treatment/Care/Support

37. I am unaware of any obstacles that my father or my son might have experienced when trying to get treatment.

38. I was never offered any counselling or psychological support. I do not know about my father or son.

Section 7. Financial Assistance

39. As far as I know, my father did not receive any financial assistance from any trust fund or fund, and I think it would be very unlikely that he would have done.

40. My mother received the £20,000 pay out offered by the Government in 2011, which I applied for on her behalf. My son also received an equivalent payment.

Section 8. Other Issues

41. Both my son and I have been approached to give evidence in the Inquiry. I have had a long chat with my son and we have decided we really don't want to give evidence. We would both feel too uncomfortable in the circumstances and would prefer to stay anonymous. My son hates talking about it all and he feels very hurt and upset about the way he was treated as a small child. He just wants to put it all behind him and forget about it, and get on with the rest of his life.

42. We made so many visits to the Oxford Haemophilia Centre over the years; especially when he was small, and we thought they were all absolutely wonderful at the time, as did my parents. In fact we purposely never moved away from the Oxford area, just because we thought the Oxford Haemophilia Centre was the best place in the whole world to be treated. We trusted them completely, and thought they had our best interests at heart. It's only now after all this information and certain letters have come to light that this has changed. My Son and I feel very hurt and upset to find out how we were really treated.

43. Although my son has suffered greatly with his Hepatitis C, he has had to reduce his working week down from five to three days per week due to excessive tiredness. After hearing from all the others in the Inquiry he feels he has come away relatively unscathed compared to everyone else. He feels almost guilty on some level, that he didn't get HIV and that he's still alive and relatively well, even though he was treated with Factor contaminated with HIV. Everyone else seems to have either lost their lives, lost loved ones or don't know how long they have left to live. We feel they should be at the heart of the Inquiry. Of course he is so grateful and thankful, and we know everyone else would be glad for him and not hold it against him, but we would just feel too uncomfortable, as so many others have suffered so much more than us. My son and his grandfather may be the only ones in the UK Haemophilia community to escape getting HIV after being treated with Factor contaminated with HIV.

Anonymity, disclosure and redaction

44. I wish to apply for anonymity. I am aware that this statement will be published and disclosed as part of the Inquiry.

45. I do not wish to provide oral evidence.

Statement of Truth

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

Signed GRO-B ....

Dated 30/8/19 ....