ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN2080001

Exhibits: none

Dated: 14th November 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 14th November 2018.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B My address is known to the Inquiry. I am living at home with my husband GRO-B and my son GRO-B: S who has moved back home after a relationship breakdown about 4 years ago. I intend to speak about my son S being infected with hepatitis C. In particular, the nature of his illness, how the illness affected him, the treatment he received and the impact it had on him, our family and our lives together.

Section 2. How Affected

2. S has been diagnosed since birth with haemophilia B. His condition is considered moderate to severe. He was tested at birth for haemophilia as this is a condition that runs in my family. It was the Royal Infirmary,

Edinburgh that tested him. They told us straight away he had this condition, which we had been expecting as it runs in the family.

3. I don't know the name of the blood products that S received. I just know that the products were freeze dried. This is information that will be in his medical records.

4. S was treated at GRO-B The Sick Kids Hospital in Edinburgh, the Infirmary in Lauriston Place, Edinburgh before it moved and after it moved he was treated at the Infirmary based at Little France Edinburgh. There were occasions he was treated at St Johns' Hospital in Livingston and possibly at the Western General Hospital Edinburgh.

5. There was an event that happened about approximately 22 years ago. I cannot remember exactly when it happened and more details would have to come from his medical records. S foot was crushed and he was treated at the GRO-B as a one off because it was an emergency, which the Infirmary didn't agree with. I remember this because Sister Billie Reynolds phoned me every single day telling me that he had to be transferred to the Royal Infirmary Edinburgh. She was arguing with me at points. I was refusing to transfer him because GRO-B was closer and it made no sense to move him all that way for their purposes. Eventually it was agreed that his treatment for haemophilia would be transported over GRO-B in a motorcycle which worked, however, looking back I now believe that the Infirmary were trying to stop GRO-B from finding out he was infected.

6. His knee ballooned up once when was in his mid-teenage years and the infirmary fought tooth and nail to get him over to them as well which I didn't understand at the time. I remember this because I had phoned a paramedic to come and take him to hospital. The paramedic came and said they wanted to give him fluids and given how swollen his knees

were, they wanted to get him over the GRO-B. I thought that's fine, and I phoned the Royal Infirmary Edinburgh while the paramedic was getting S into the ambulance. I thought I was doing the right thing by letting them know that S was going to be admitted there. The Royal Infirmary was not pleased at all. I spoke with Billie Reynolds that time as well and she told me to get S over to them, straight away. I ran down to the paramedic and said to him that the Royal Infirmary wanted S to be admitted there. He then spoke with the hospital and had a very vocal argument with them about it over the phone. At the end of the call the paramedic slammed the phone down so hard, the handset, which was attached to the wall, fell off the wall. The paramedic then told me that Sister Reynolds had spoken to him in a really bad way and he was furious as his professional judgement was being questioned. He did however follow their instructions and drove S to the Royal Infirmary that time. Now I presume it was so that the GRO-B would not realise he had hepatitis C. That is what I believe anyway. This is the type of response they would always give if there was any question of S being treated elsewhere. The hospital he has been treated at the most is the Royal Infirmary Edinburgh.

7. I presume he has received products from when he was a toddler maybe 18 months – 2 years old, so approximately 1980 and then we were told about his diagnosis when he was 15 years old in 1993. S was born in 1978. It really depended on when he had a bleed so he could be in hospital at points almost every day and at other points there would have been large gaps between receiving the products. This will be information that will be contained in his medical records.

8. I was given no information about the risk of S being infected by receiving these products. We thought we were doing the right thing by him. We trusted the doctors, you believe in what they say. You always believed the doctors would know what is best.

9. S was diagnosed with hepatitis C when he was in his last year at school. He was 15 years old, so around 25 years ago approximately. I cannot recall a specific date. The doctors did conduct an AIDS test and he wasn't infected. I believe this test was done after S was diagnosed with hepatitis C. I think this because I cannot recall any conversation about AIDS with Professor Ludlam and Dr Hayes, the Liver Consultant when S was diagnosed with hepatitis C. I cannot recall when he was tested for AIDS, I just remember he wasn't infected. It was just hepatitis C he had. We had to have an AIDS test, but we were never offered a hepatitis C test. The Royal Infirmary at Edinburgh offered us the AIDS test. We don't know why we weren't offered the hepatitis C test and we didn't ask.

Finding out about infection

10. We received a letter from the Royal Infirmary Edinburgh when S was in his final year at school approximately 20 plus years ago. S was 15 years old at the time. They wanted us to take S in for a check. We didn't think too much about this because we were always receiving letters from the hospital arranging appointments to see the dentist or the doctor, standard things like that. This letter asked us to go and see Mr Hayes, who was the liver consultant. It was S last year at school and he had been out of school a lot because he had been very unwell that year. He asked me if he could go to school instead because he had missed so much. The letter didn't say it was an emergency or anything, it was just an ordinary appointment letter. I phoned up and cancelled it and made another appointment.

11. We ultimately went over and my husband GRO-B stayed in the waiting room. S and I went in and spoke with Dr Ludlam and Dr Hayes. They just told us the diagnosis and I didn't have a clue what this meant. So I asked if GRO-B could come in to the appointment. GRO-B came in and they just said to us that S had hepatitis C. We had no idea what this meant. The only other information we were provided in the

appointment was that it was non A, non B hepatitis. They just didn't say anything else. We drove home from the hospital in complete confusion about what this meant. Because this had left us so uncertain, we made an appointment with our own GP which is GRO-B GRO-B GRO-B about it and at that point there must not have been a lot of information available because our GP said to us not to worry about it and that was the end of it.

12. Other than the conversation with Dr Ludlam and Dr Hayes there was no further information at that time. No follow ups or anything. Life continued on as normal.

13. I don't think adequate information was provided. At that time, I trusted the doctors. I believed what a doctor would tell me.

14. We should have had information that was a lot earlier. As soon as he was infected we should have received information. My son had the right to know. I truly believe there has been a cover up. I think the NHS and government knew about the blood from America. Whoever it was that brought the blood over from America should have been questioned. They got blood from the American prisoners, they just didn't care.

15. The way the results of the tests were communicated was done in a way that made out that it was not important. My mind was blank when we were told. My son was 15 or 16 at the time, so he didn't understand what was going on. We didn't discuss it with him because we didn't know what to discuss. Even the GP didn't know anything to discuss. Life continued on as normal, but it was always in the back of my mind for a long time. I suppose now that things affect S more, it is something I think about a lot more.

16. We were just told by the doctors at the hospital that you could only get it from your blood coming into contact with hepatitis C blood, that was it. No further information was provided.

Section 3. Other Infections

17. I am a little unsure about this. I don't think there are other infections that I can think of but S has received a letter indicating that he may have been exposed to variant CJD, mad cow disease. I don't know when this letter was sent or where it was from. It was a long time ago. This information I would hope would be contained in his medical records. Other than this letter, there was never any more communication about this. We don't know if he has this.

18. S makes a joke of it "*If you see me in a field eating grass like a cow, shoot me*". It is tongue in cheek but it is very upsetting. I was disgusted by the letter that he could have been infected with something else. The only other conversation we have had about this is him asking "*Mum, what else are they going to give me*?" I felt sorry for him when he said that. I blame myself sometimes because I took him every time he had a bleed and thought it was right, but in fact I took him somewhere to receive something that has negatively affected his life.

Section 4. Consent

19. I believe that he has been treated without his knowledge. I believe this because he was told he was infected but never advised about any tests that they were conducting. Every time he attended hospital they would take a lot of blood but they never told S or I what it was for. They just took it and we trusted them.

20. I believe the hospitals never obtained his consent. They did the test, but they never told us of its existence. We trusted the doctors. If they asked for blood we let them without question. I don't trust doctors now.

21. We were never given adequate information at the point of S diagnosis. GRO-B and I have never spoken to anyone since that

conversation on the day Dr Ludlam and Dr Hayes told us about his diagnosis. I certainly cannot recall a time when further conversations took place or further and adequate information was provided.

22. Yes I believe that probably his blood has been used for research purposes. I think a lot of the infected have been used for research purposes, I base this belief based on own gut instinct.

Section 5. Impact

23. S cannot concentrate on anything. He is on anti-depressants now. He lost his job as a GRO-B in November 2017 because he kept having to take sick days. His relationship broke up about 4 years ago and now he sits in his room a lot. He doesn't go out at all. It is not the way we want him to be. We want him to go out and enjoy his life.

24. He is in pain constantly, nothing specific, it is a constant niggling pain that he has. He is always complaining about different pains that he has now for which he takes pain medication. He is on co-dyramol (BAN), tramadol and dihydrochloride. The pains are not specific, sometimes it is hard to pinpoint the pain. It tends to be swollen joints or stiff joints.

25. He does take pain medication now and he is on anti-depressants. I don't know the name of the anti-depressants he takes. He has been on them for a long time now for many years. I don't know when he started taking the anti-depressants, because he didn't tell us for a long time. I think he was embarrassed being on anti-depressants but he did eventually tell us. I would not be able to say when though. He doesn't talk to me about how he is feeling.

26. I remember he had a very serious accident when he was 18 or 19 years old, when his foot was crushed. When he was released from hospital, he was in a wheelchair. I wheeled him outside to the front door so he could get some fresh air. He refused and insisted that he had his back to the

pavement so he could not see anyone and nobody could see him. He did this because he was embarrassed, he didn't want to face anyone, he hated being in a wheelchair. He didn't want his friends to see him.

27. He seems to get every infection going now. A lot of colds and bugs. He has arthritis now in his foot. His foot was crushed when he was in his early 20's in a GRO-B and ever since then he has had arthritis. He has arthritis in his knees as well, but this is due to operations he has had on his kneecaps at the Royal Infirmary or St John's Hospital, Livingston. His medical records will have to confirm which hospital it was and when this occurred. I am not sure why he had his kneecaps replaced. He is not formally diagnosed with anything else, but he is always tired, always drained.

28. He is not very well. He takes everyday as it comes. He has lost the will to live. He just doesn't see the point in trying to do the everyday things like work and going out that most people do. He is frightened at what the Edinburgh Royal Infirmary will throw at him next. He tries to avoid contact with them at all costs now. He no longer goes there for any appointments and only goes if he has a really serious bleed. The hospital hasn't bothered to keep in contact with him either so they don't monitor anything for him now.

29. He doesn't lead a normal life not for someone his age anyway. He just sleeps now and stays at home in his room. I don't know if the treatment in S teenage years was successful or not, I cannot recall. I have a feeling S told us the treatment had not worked, he won't talk about it now. He is in denial about the whole situation. He puts the hepatitis C to the back of his mind now. Now he only goes to hospital if he has a bleed and has no choice. He tries not to go to the hospital now. He suffers longer than he really needs to. It usually gets to the point where I have to force him, before anything happens. He just does not trust the doctors at the hospital he wants as little to do with them as he can.

30. S received treatment in his teenage years. It was in the 1990's. He would receive injections several times a week in his stomach. It was Interferon and Ribavirin. I cannot recall how many times exactly every week he had to inject, it has been so long now. That was difficult. He found it too hard to inject himself. My husband GRO-B injected S in the stomach. I couldn't, I found that too hard. S was on this treatment for a long time, I cannot recall how long he was on this treatment for, this information will be in his medical records.

31. There were no difficulties in accessing treatment. The treatment was not offered straight away to S is my only comment. I really cannot remember when he started treatment. I know it was not straight away, this information would have to have come from his medical records. I can't remember if there was a delay in starting treatment or if it started within an acceptable time frame.

32. S did not face any difficulties in accessing treatment. The treatment did not start instantly; I cannot remember when it started. This information would be in his medical records. What I can remember is that S has not told us if the treatment has worked or failed. S does not speak with the Royal Infirmary, Edinburgh unless he absolutely has to now. He has fallen out of contact with the doctors at the Royal Infirmary, Edinburgh and the hospital have not kept in touch with him to the present day.

33. There were a few mental and physical side effects, on the treatment. It was a fairly difficult treatment. He used to hate getting the injections. He used to complain a lot about how it made him feel sick and tired. He would complain that it was too hard to inject himself in the stomach. I couldn't help with this. Injecting him was just too hard. I didn't want to hurt him anymore than he already had been hurt. While he would complain about it, he would always allow my husband, GRO-B to inject him. He wasn't very keen but he did understand, it was necessary. He would complain a lot about it. The hospital doesn't keep in touch with S

so he has never been offered the new treatments. I remember during the treatment S was hardly ever at school. He was at school so little; the school gave him a home tutor. Mentally I can remember he started fishing during the treatment. This was something that he could do but we think it was something that allowed him to isolate himself from everyone else during the 1990s. He didn't want to go out and see anyone.

34. The infection did have an impact on other health conditions. S used to attend the dental hospital based in Chalmers Street, in Edinburgh because of his haemophilia. He used to go into a normal room with everyone else but after he was diagnosed with hepatitis c he was put into a room on his own and everything in the room was covered in plastic. It was like something out of a space film. I wondered what was going on the first time. I think someone explained the reason for the plastic was because of his hepatitis but I could not tell you the details of this now. He did meet a nice dentist called Mr Hazard, but this dentist left the dental hospital shortly after S started treatment there. I am not sure when Mr Hazard left the dental hospital. He did not want to go back to see anyone after this and I am sorry to say his teeth are now disgusting. He needs a lot of work done on his mouth. He is really embarrassed about his teeth now.

35. The nurses and doctors at hospital did not treat him differently when he was infected. He used to get on really well with Rosie Dennis who was a Consultant based at Edinburgh, Royal Infirmary.

36. S was embarrassed having hepatitis C. He didn't tell anyone at school. The only people he has ever told has been people who had to know, like family and his former partner GRO-B Sometimes he will tell people he has haemophilia but mainly he doesn't discuss anything to do with his blood if he can avoid it.

37. I never thought there was anything to be embarrassed about having hepatitis C until I spoke with my sister in law. I told her that S had

been infected. We were both GRO-B She said that I couldn't work with her again in that case. She thought because S had this that I could infect her at work. I learned after that, to keep my mouth shut and not tell people about the hepatitis. That did cause a lot of tension with our family but we are on speaking terms. It felt very shocking and hurtful when this happened. People were ignorant at the time. He doesn't want anyone to feel sorry for him though.

38. There has been a big emotional and mental impact on GRO-B and I with S being infected. I'm on anti-depressants for about 7 years now myself. Something was in the paper about the Infected Blood Inquiry then and whatever the detail was, it was enough for me to realise it was all too much. This Inquiry brings it back again as well. It can make me cry if I think about it for too long. If I hadn't had any children he wouldn't have had this infection. I have felt guilty for a very long time. The idea that I could outlive my son, it is too much. I am disappointed with the Royal Infirmary Edinburgh as they could have told us earlier than when they did. Why lie? Why pretend he was fine when he was infected? Didn't he have the right to know? Didn't we as his parents have the right to know? If the hospital had told us about the risk of infection I wouldn't have been so keen to get the treatment for his haemophilia. Every time he bled, I would instantly say, right ok let's get an ambulance and get this treated. The Royal Infirmary Hospital in Edinburgh always insisted on being the ones that treated him. He was under the care of Professor Ludlam there.

39. S was hardly at school. He had so many bleeds it kept him off a lot. He was ill at this time and missed a lot of classes as a result. He would have a lot of problems with bleeds. At one point a school inspector came out to find out the reason he was missing so much school. As a result of that, the local authority sent him a tutor to catch up. This didn't work though. He left school with no qualifications S started his job with GRO-B at 16 years old as a GRO-B He did the job until his foot was crushed. He went off on long term sick after this and

they paid him off the first time. I cannot remember when. He remained unemployed until his mid-20's when he went back to work then again when he was 24 years old, again as a GRO-B He then worked with GRO-B He was fine at work, but he had a lot of time off. They didn't understand, what the matter with him was. It was not serious things, it was regular situations where he would not be feeling right that day, feeling a bit off colour or his joints were sore.

40. About a year ago this month he was made redundant. He did tell work that he was a haemophiliac. He didn't tell them he had hepatitis C. He was too embarrassed. His work couldn't appreciate the nature of haemophilia. They didn't seem to understand that if he had a bleed, it could be an internal bleed and cause all sorts of issues. He doesn't want to look for work now. He doesn't have a degree; he was a GRO-B He only got that job because of his dad. GRO-B used to be a GRO-B as well and worked beside S and could keep an eye on him. His confidence is very low now.

41. After my sister in law's reaction when we were GRO-B I didn't tell anyone. There was not an impact to my work. GRO-B and I would always make sure that we worked our shifts to ensure someone was always with S

Section 6. Treatment/Care/Support

42. There were no obstacles in facing care, support and treatment for S GRO-B and I would always do the day to day things for the household, shopping and cleaning. We always made sure S had what he needed.

43. No counselling or psychological support was ever offered to myself, GRO-B or S Thinking back if I had been offered support I would not have accepted this in all likelihood because we tend to deal with things

ourselves. I don't believe that S would have gone either, for the same reason. He has changed though. S is not the same person since finding out he has become infected. He is a lot more isolated, withdrawn, quiet. He is much more reluctant to engage with the world.

Section 7. Financial Assistance

44. I don't remember how S found out about the existence of the Skipton fund.

45. S got a £20,000 one off payment and a £30,000 one off payment from the Skipton Fund. He gets £600 per month now from one of the Trust Funds, I am not sure though, I think it is the Skipton Fund. I think he will in the near future get a payment from the SIBSS. He got a letter from them recently setting out that he will be getting an annual payment from the 15th December 2018. We don't know how much this will be for.

46. S didn't do anything to apply for financial assistance from the SIBSS. They just got in touch with him because he was registered with the Skipton Fund. I believe he completed a form for Skipton but I don't know what was required for this.

47. There weren't any obstacles for S in applying for financial assistance.

48. I have a feeling that the payment made to S from the Skipton Fund was a one off payment that meant things were brought to an end and that after the £20,000 and £30,000 there would be no more money. I think he had to sign something to this effect which indicated that this was a one off payment and that he would not get any more money.

49. The amount of financial assistance that S has received is nothing. It is nothing compared to what the NHS have done to S life. The

money he has received is about 2 or 3 years' worth of wages for a good job. They only got £50,000 for ruining their lives and shortening their lives. People with hepatitis C have a life expectancy 10 years shorter than others. They are due a lot more.

Section 8. Other Issues

50. We understand that Thompsons are requesting S medical records and would be interested to review these with S once he is provided with a full copy.

Statement of Truth

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

Signed GRO-B

Dated 17. 12. 18