Witness Name: GRO-B
Statement No.: WITN2081001
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 the 14th November 2018.

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

Section 1. Introduction

1. My name is GRO-B. My date of birth is the GRO-B 1955. My address is known to the Inquiry. I am a GRO-B GRO-B GRO-B I intend to speak about my son GRO-B: S GRO-B: S illness of hepatitis C. In particular, the nature of his illness, how the illness affected him, the treatment received and the impact it had on him and our lives together.

Section 2. How Affected

2. S is a haemophilic. He was born with haemophilia, as GRO-B, his mum, is a carrier. He has type B and is considered between moderate and severe.

3. I don't know what blood products he received. Possibly one of the Factors, possibly Factor 8 or 9, but this information should be in his medical records.

4. The first time S was at hospital was when he was at the Sick Kids, Edinburgh. He was about 15 months/ 2 years old at the time. He had a bleed in his mouth and was treated there. After this incident, he was always treated at the Royal Infirmary, Lauriston Place, Edinburgh until the hospital moved to Little France, Edinburgh in 2001 or 2002. The Haemophilia unit at the time in the 1990's was fairly small which we believe is the reason he was treated there and not at the Sick Kids Edinburgh. I always remember thinking, he was a little boy, being treated in a man's ward. He was a tiny child in an adult bed. He was also treated at Queen Margaret Dunfermline when he crushed his foot about 22 years ago. He was about 18 years old when this happened. This would have been about 1996. He has been treated at St John's Hospital, Livingston, as well to have a wisdom tooth in 2004 approximately. He has been at several hospitals in his lifetime. I cannot recall the names of the doctors involved in prescribing the infected blood products to S. Information on this will have to come from his medical records.

5. S could have received the infected blood products at any time from the period of 15 months old to 15 years old when he was diagnosed. I do not know specific details of this. I would hope this information would be contained within his medical records.

6. Due to S haemophilia he would have periodic bleeds which required treatment to help his blood clot. At some point between being 15 months old to age 15 years old S received an infected blood product for one of his bleeds and was infected with hepatitis C.

7. I cannot recall any conversation ever about the risk of S becoming infected with anything as a result of receiving the infected blood products.

8. We found out that S was infected at one of his appointments at the Royal Infirmary, Edinburgh Little France. I usually wait outside in the waiting room during these appointments. This time, part way through the appointment, my wife asked if I could come and sit with S and her due to information that she had been given in the appointment saying that S was infected with hepatitis C. I didn't understand what that was but I remember that Dr Hayes, the liver specialist and Dr Ludlam the consultant on the haemophilia unit, said that this was a condition that could affect S liver. They said it could do damage to his liver in the long run and cause cirrhosis. I remember asking "*Does this mean I will outlive my son*?" I think they may have said something like "*It might not be that bad*", or "*We don't know*". That was basically it.

9. The story above explaining how we found out S had hepatitis C, is all the information we ever received. After the conversation saying he had this, we went home. There was no information about what hepatitis C meant and what practical things had to be put in place for him. The doctors really acted like it was not a big deal. It felt like the downplayed things.

10. Adequate information was not provided to manage the infection. The doctors, the day they diagnosed S, didn't go into any detail about what could happen to S in the future. Still to this day, we don't have a comprehensive understanding of what the illness involves.

11. Information should have been provided much earlier. GRO-B and I wouldn't have taken S over to the hospital as often as we did with nose bleeds if we had known the risk. When he was younger he would have a lot of nose bleeds. Those bleeds were severe. He was haemorrhaging when he had these. They could have been cauterised though. Maybe we would have held off on taking him to hospital until we had no choice, however we always thought it best for him to receive treatment. If we had realised about the risk, we might have thought twice about this. Maybe he would not have caught hepatitis C then. As his parents, no information was ever given to us in full. Between the ages of 1 and 10 years old, S was over to The Royal Infirmary, numerous times. He only attended the Sick Kids, Edinburgh once. This was when he was 15 months old. After that it was always the Royal Infirmary Edinburgh. S was under the care of Dr Ludlam from when he was 15 months old onwards.

12. My view on how the results of the test was communicated to us is that only when GRO-B was 14 or 15, did we find out that he had been infected with hepatitis c. We were angry obviously not knowing what this entailed and how it was he had caught this. I didn't realise the full extent of what was going on at the point. S was diagnosed and I still have questions about the illness, what could happen in the future for S and where did the infected blood come from?

13. After S was diagnosed, there was never any other meeting with the doctors. Therefore, there was no conversation with anyone about the risk of others being infected as a result of infection.

Section 3. Other Infections

14. We have been told by a letter, in 2009, that S probably has Variant CJD. Apart from this letter warning him that there is a chance of this, we never got anymore more information. We don't know if he

has in fact been diagnosed with this or not. S didn't have any follow ups with the hospital to see if he had anymore diseases. He has made the joke "*If you see me eating grass in a field, then just shoot me*", but it's not funny. Apart from this joke, he has never spoken about this letter again. I think it must have upset him, because that is an extremely upsetting letter. Other than the joke he made, he has never discussed the effect it has had on him.

Section 4. Consent

15. I do believe that S has probably been tested or treated without his consent. Every time he was in hospital at Little France, Edinburgh, the doctors always took samples of blood from him when he was there and did not explain why. Whether this was to monitor his levels or for testing we don't know for sure.

16. I do believe that he has been tested or treated without his consent. They took a lot of blood and certainly they did not seek consent when they tested him for hepatitis to begin with.

17. I believe S has been treated or tested with being given full adequate or full information. There has been no information at points. The doctors never told us anything, unless they absolutely had to. The only real information GRO-B and I have ever had has come from this one meeting when he was diagnosed at age 15 at the hospital with Dr Ludlum and Dr Hayes.

18. I do believe that S has probably been treated for the purposes of research. I don't have evidence in relation to this I just recall that the doctors took a lot of blood all the time and it makes sense that they were testing his blood for research. I do not have explicit evidence of this.

Section 5. Impact

19. There are a lot of physical and mental effects for hepatitis C on S. His concentration is not there now; his memory is very poor. If he is going to the shops, he has to write himself a list otherwise he will get to the shop and have no idea what he needs, which he finds very frustrating. He is tired a lot of the time. He has not got a lot of interests now apart from fishing and his car. He doesn't socialise, he doesn't drink apart from the occasional bottle of beer. We think he chooses not to drink, because he has a fear about his live. The fear is that it may deteriorate one day. He has a lot of aches and pains, nothing specific, he just makes comments about having sore shoulders or feeling stiff a lot.

20. S has arthritis in his ankle now, this may come from his foot being crushed though. He is always complaining about his shoulder being stiff and sore but he does not have a formal diagnosis.

21. S is not outgoing. Through having the illness, S has lost a few friends, but he does still have loyal friends now. A lot of his friendships fell apart over time after he was diagnosed due to the more withdrawn he became. He just lost contact with a lot of his school friends. He is depressed now. He was diagnosed with this many years ago, I could not tell you when. Every day is different. One day he could be normal downstairs talking to us and out and about and the next day he is up in his room the whole day.

22. S was on Interferon treatment and Ribavarin treatment when he was a teenager. I used to have to inject him in the stomach, which physically hurt him a lot. I didn't like doing it but it was necessary for him to get this treatment. I can't remember how often he was on this treatment. It was for a sustained period of time. He hated getting it done. The treatment made him very unwell, he was sick a lot and

sleeping a lot. He was rarely at school. He didn't discuss with me how this made him feel.

23. S did not face any obstacles to treatment. The only comment about this that I can make is that the hospital didn't offer the treatment straight away. I am not sure about the period of time between being diagnosed and S starting treatment. I think this information will be on his medical records.

24. The treatment offered to S of Interferon and Ribavirin, was what was available for hepatitis sufferers at the time I believe so it was appropriate.

25. There were several physical and mental effects. Depression for one thing. When he was having treatment he just seemed to give up the fight and stop caring. He became very withdrawn and very depressed through the treatment. Physically, S spent the whole period on treatment like he had a permanent cold. He felt under the weather all the time. It was like this all the time until he stopped treatment and went back to normal. I can't remember how long S was on treatment for. Maybe about 6 months.

26. When S went to the dental hospital in Edinburgh, he was usually in a big main room with everyone else. After he was diagnosed the first time he returned to the dental hospital he was escorted downstairs into a room covered in plastic. After that he had one to one treatment with a dentist called Mr Hazard. That was fairly unusual with the plastic room. Apart from that though, Mr Hazard was always very good with him.

27. There was an impact to our family, social and private life. We never told anyone apart from my sister in law GRO-B GRO-B. Her reaction was very bad. GRO-B GRO-B. The impact of that event was that we never told anyone to

anyone else. We would go and visit my side of the family but they would never come here. The event with my sister in law did cause tension. It was never discussed again though. It was swept under the carpet. S did not discuss the illness with his friends and doesn't tell people even now. S does not go out at all, he is very quiet and withdrawn in himself. His relationship has broken down about a year ago, which meant he had to move back home here. His ex-partner would get frustrated with S a lot because he was constantly forgetting things that she said. She would accuse him of ignoring her and not listening. S would also get very tired very easily and this annoyed his ex-partner as well. She would accuse him of being lazy and not bothering. Ultimately it led to the end of their relationship.

28. After S was diagnosed, holidays for us as a family were always a nonstarter. Every time we would even think about a holiday, S would have to go back to hospital so we rarely found ourselves being able to get any sort of break.

29. S used to have a lot of friends but these friends have fallen away. He has some close knitted friends now only. I think his friends might have found out he was infected but I have no memory of it ever being used against him by his friends.

30. When S was at high school, he ended up requiring a home tutor. It did not make a big difference though because he ended up leaving school with no qualifications at all. This was because he was off school so much due to his hepatitis and haemophilia. GRO-B GRO-B. That was fine, except he had a lot of time off. It was because he couldn't do the job, like a normal person. The haemophilia would mean he would have to take maybe a month off to recover from a fall or a knock due to the tissue damage it would cause. The GRO-B GRO-B I don't know how much detail GRO-B explained to them. As far as

GRO-B is concerned he was not capable of doing the job and he was made redundant about a year ago.

31. There was not a big impact on my work. It was not a thing that I would broadcast at work. I did not have to take time off as GRO-B and I worked out a way that meant, that someone could always be with S

Section 6. Treatment/Care/Support

32. S received a home tutor from the local authority when he was unable to go to school. Other support has always been in the form of GRO-B and I. We did everything else for him that was needed, which was fine to be honest.

33. S has never been offered psychological support. Neither have I. Not that I can remember. Maybe if S had spoken to someone this would have helped him cope when he was younger. I do think he would have been reluctant to go so I don't know if this would have worked for him. I am unsure if counselling would have helped me as I tend to get on with it.

Section 7. Financial Assistance

34. I don't remember details when S found out about financial assistance. GRO-B deals with these kind of things and should be able to answer this.

35. I don't know what payments were made. What I do know is that S got lump sums, I believe from the Skipton Fund that he very quickly spent. My wife, GRO-B tells me it was £20,000 and £30,000.

36. I am unable to answer the question about the process of applying for financial aid as my wife GRO-B and S dealt with this.

37. I am not aware of any financial obstacles that S faced in applying for support.

38. I have no awareness of any preconditions for the application for financial assistance.

39. I do not have any further comments about the money aspect of matters. I believe it is difficult to put a price on someone's life.

Section 8. Other Issues

40. I have nothing further to add to this statement.

Statement of Truth

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

Signed GRO-B

Dated 17 . 12 . 18