Witness Name: GRO-B
Statement No: WITN2244001
Exhibits: None
Dated: 10th December 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 6th November 2018.

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

Section 1. Introduction

1. My name is GRO-B and my date of birth is GRO-B 1952. My address is known to the Inquiry. I am GRO-B: S mother. I intend to speak about my son's experience of being infected with hepatitis C upon receiving infected blood products. In particular, the nature of his illness, how the illness affected him and me, the treatment received and the impact it had on him and our lives together when he was growing up.

2. My son was born on GRO-B 1974. We have always been close. Haemophilia runs in my mother's family and my brother had it. Haemophilia is hereditary. When I was younger, I

used to work for the Blood Transfusion Service and I had a blood test before I was pregnant with S The result of this blood test was that I was a borderline carrier for Haemophilia, but the Blood Transfusion Service could not give a definite answer as to whether or not I would pass the disease on to my children. Later on, when I was pregnant with S I attended pregnancy classes. I was offered a blood test in the context of my pregnancy classes. The result of this blood test was that I was not a carrier for haemophilia. It turns out that I was actually a carrier and I passed it on to S When S was born, he sustained internal bleeding in his head. S is an only child. I decided not to have any more children because I would not risk the chance of passing haemophilia on to them and, if I had a daughter, she could pass this on to her own family.

Section 2. How Affected

3. When S was growing up, we were at the hospital constantly up until he became five years old. It was when S became five that I learned how to administer injections myself, but until then we were at hospital every couple of days due to his haemophilia. We also used to attend Yorkhill Hospital in Glasgow once a month for family meetings.

4. I would say that S has severe Haemophilia A. He has no percentage or less than one per cent clotting factor in his blood.

5. From birth and until ages 4.5 or 5 years old, S received cryoprecipitate. Then he starting taking bad reactions to that and was given factor 8 instead. He still uses factor 8 as a blood replacement product.

6. S attended Yorkhill Hospital for sick children until age 14. Then he was transferred to the Royal Infirmary in Glasgow. At Yorkhill, he was treated by Dr Anna Pettigrew, Mr Watters and by a Dr Hans. At the Royal Infirmary, he was treated by Dr Alvie, Professor Law and Mr Campbell Tate. However, at both Hospitals it was mostly nursing staff that dealt directly with S. I am not sure of all the names.

7. I believe that [redacted] was first given infected blood products between ages 8 and 10. Whenever any blood tests were done, we were always told that these tests were routine and even though we used to ask frequently, we were never given definite answers. [redacted] was never told that he was infected until he was 20 or 21 years old, and he was still receiving factor 8 at the time. At age 12 or 13, [redacted] started self-injecting, but between ages 5 and 12, it was me who injected the factor 8. When [redacted] was first told that he was infected with hepatitis C, we had never heard of this disease before.

8. At some point, we were told during one of our family meetings at Yorkhill Hospital that they were trying a new blood product imported from America that was going to be given to children, but not to adults. [redacted] must have been 7 or 8 years old when we had this meeting. No choice was given, we were just told that the new blood product was better for children. No details as to the donors that this blood came from were provided. The donors were paid for donating blood. We were told that the product was going to be heat-treated to remove any infections or viruses. We were also told that the treatment would not be as effective and a higher dosage would be required to clear internal bleeding. However, the doctors decided that was the best treatment, that was the treatment that children were going to be given and families did not have a choice.

9. No warning was given about the risk of being exposed to infection. We were simply told that the new product was not as effective and that a higher dosage of the product would be required for it work.

10. [redacted] was only infected with Hepatitis C and not with HIV or any other infection. A lot of the other children were infected with AIDS or other viruses and have now died. In the last few years, [redacted] has been told about the risk of having been infected with mad cow disease, but we do not know whether he is actually infected.

11. [redacted] found out that he was infected with hepatitis C at a routine clinic appointment at the hospital, and it was Professor Law who told him. Every six months, [redacted] went for normal clinic check-ups at the hospital. He was told that he had been carrying hepatitis C for years. There is a letter from [redacted] GP that proves that the GP had known about

the hepatitis C for years, long before S started work, but S was never told about it. We don't know why they chose to tell him when they did and not as soon as they knew. My late husband, S father, was also told about the hepatitis C at the time and S was recommended to have a liver transplant in 20 years' time. The news came as a shock to us. S was really depressed for about a week or so after finding out that he was infected with hepatitis C.

12. S was told that he could go to counselling. Hepatitis C was new to us and we did not know the implications. At the time when he was first told that he was infected with hepatitis C S was only told that the illness would affect his liver. It was also explained to him that he had come to be infected through contaminated blood products.

13. No information was provided to understand and manage the infection, other than the doctors telling S that he could attend counselling to learn how to manage his infection from a psychological point of view. He was also told that alcohol would affect him negatively and that he would be experiencing tiredness as a result of the infection. This is as far as I can remember. S was advised to cut back on drinking. S chose not to attend counselling, so I do not know whether the NHS would have funded it.

14. My opinion is that they should have told S that he was infected with hepatitis C as soon as they knew about it rather than try and conceal it. S was a child when he was infected, but he was 21 years old by the time he found out that he was infected.

15. How the information about the infection was communicated to us was an absolute blow. It was horrible to get taken in to see the doctor only to get hit with that information. It was a shock to S father, too. I do not think there is any other way that they could have told us, except that they could have told us a lot earlier.

16. S was told about the risk of transmitting hepatitis C through bodily fluids, for instance through intercourse. I do not know whether kissing would pass on the disease. It would not affect any person drinking from the same glass as S. He was told that he could pass it on and he had to be careful.

Section 3. Other Infections

17. I do not believe that S received any infection or infections other than hepatitis C. There is, however, still a risk that he might have been infected with mad cow disease. This is still a risk nowadays, although it is not as high because his blood products are synthetic rather than from actual donors. I think he could have been infected with mad cow disease because of the previous blood products that he has used in the past, not because of the blood products that he is currently using. Again, we were not informed that there was a risk that S might have been infected with mad cow disease until this illness attracted the attention on the media and it was everywhere.

Section 4. Consent

18. I confirm that I believe that my son was treated or tested without our knowledge, without our consent, and without being given adequate or full information.

19. I do not know whether my son was ever treated or tested for the purposes of research. He could have been and it is possible that he was. However, I could not say as we were never fully informed. S himself could perhaps answer better. The reason I say that my son was treated and tested without his or my knowledge, consent and without information is as follows. Every time I took S as a child to Yorkhill Hospital for his haemophilia he had blood taken. I always asked why they were taking S s blood and I was told that it was just routine. You do not think to question medical

staff as you assume they know what they are doing. I didn't object to the blood being taken and obviously as S was only a child neither did he.

Section 5. Impact

20. As a result of being infected with hepatitis C, S's liver has been affected. We do not know how badly his liver has been affected as he cannot have a biopsy due to the risk of bleeding and is no longer receiving liver scans. I believe that he is borderline between stage 1 and stage 2 of cirrhosis of the liver. When S was 21 years of age he was told that he was infected with hepatitis C, S mood went straight down for over a week. He did not want to see or speak to anyone and he locked himself in his room. He thought that he was going to die. Being told caused a big shock which lasted for over a week. His father, his best friend and I all had a chat with him until he came round. We all told him that his illness was not going to affect him or us, and encouraged him to go on a holiday with his friend that had been planned for a long time. If it had not been for the fact that we spoke to him, he would have decided not to go on holiday. We encouraged him to learn to live with the illness. Except for family, he did not want anyone to know, not even people at work. For a young person, S would sleep all the time. If he ever went on a night out, he would be home by 11.00 p.m. We never encouraged him to practise sports because of the haemophilia. He did try going to the gym but could not last long because he had no energy. He was constantly and permanently tired.

21. Because of the infection, he was offered a treatment called Interferon, which he attempted. He had an injection to his belly daily and could not drink any alcohol for a period of six months. He was on this treatment for about five weeks and he had a bad reaction to it. He was covered in spots. This was in the late 1990's but I cannot be more specific than that. Later on, he was offered another treatment, also Interferon. This also consisted of an injection and 15 tablets per day. It had awful side effects. His hair fell out, and he kept being sick and shaking as if he had a cold. He wanted to stop this treatment a few times, but he was persuaded to do the full six months of treatment,

which made him very ill. This was 5 or 6 years ago. The hepatitis C virus is cleared now, but there are still parts of the infection in his brain. I don't understand these things, but he will never be cleared of hepatitis C. The treatment has slowed the process down, but it is not an actual cure.

22. The course of S illness is that he was constantly tired, had no energy and was always sleeping. It has always been the same, there has never been any improvement or deterioration.

23. S has only ever had the two treatments already discussed, with the implications and consequences that have been described. He got both treatments from the Glasgow Royal Infirmary, they supplied everything. He got the tablets from hospital and was able to self-inject at home.

24. I do not think he ever faced any difficulties or obstacles in accessing either of the treatment.

25. I do not know whether there were any other treatments available to treat hepatitis C, other than the treatments offered to S

26. The main effect that the treatments had, apart from rashes, hair loss, sickness and the other symptoms that I have already mentioned, is that S became very depressed and constantly tired throughout both treatments. This was particularly bad when he had to stop the first treatment because he knew that it had not worked and felt like nothing was ever going to help him. The second treatment made him so sick that he wanted to stop it as well, but the hospital persuaded him to keep going until the treatment was complete.

27. Whenever S goes to the dentist, it must be at the Royal Infirmary. No other dentist will take S because of the haemophilia combined with the hepatitis C. Even when he has his teeth cleaned by the hygienist, he needs factor 8. He could never attend a private dentist. If he has any other issues, such as a sore throat, he will go to

his GP, but they already know of his condition and they know how to treat him. Most of his visits are to Glasgow Royal Infirmary, just to deal with his haemophilia. He has a lot of internal bleeding, but I do not think that the hepatitis C has contributed to making his internal bleeding any worse.

28. Being infected with hepatitis C has had an impact on S private, family and social life. As concerns his social life, hepatitis C means that people have kept their distance for fear of becoming infected. Growing up, S never told any of his girlfriends about the hepatitis C. He did tell his wife, GRO-B However, I am pretty sure that I will never have grandchildren. I do not think S GRO-B will ever have children, but that is for them to decide and it is none of my business. I think they fear that, if they had a baby, he or she would be born infected with hepatitis C.

29. S hepatitis C has also affected me. I felt guilty for giving him his treatment, but if I hadn't given him the injections, then the hospital would have done it. S already had enough to deal with without them giving him hepatitis C. I was brought up with a haemophiliac brother who died at the age of 26. Haemophilia was not new to me. However, haemophilia was new to my husband. He wanted to wrap S in cotton wool. My husband was constantly worried that S might die. Nevertheless, the treatment which caused my brother to die was improved and S did not die. Despite this fact, my husband was very depressed when he discovered that our son had been infected with hepatitis C as our son was only a young man.

30. There was a stigma about having the disease as well. When S was 21, he was told about the hepatitis C, but even before that AIDS was all over the news and when he was growing up his teachers would want to speak to me about his cookery classes and other issues. They were concerned about my son sustaining a cut peeling potatoes or taking part in any other activity and spilling blood, causing someone else to catch some disease. No one even knew that S was infected with hepatitis C back then, but the news on the media cause people to be alarmed when dealing with haemophiliacs. I simply told S teachers that S was exactly the same as any other pupil, but I did not know about the hepatitis C at the time. Just because they had seen on the TV that

haemophiliacs are more prone to catching AIDS or HIV did not mean that S had these illnesses.

31. S was 21 when he found out that he had hepatitis C and he was already in employment at the time. He initially wanted to GRO-B GRO-B This had always been his dream, however, S was unable to GRO-B GRO-B due to his haemophilia. He was also unable to engage in any sort of manual work. S GRO-B and does office work. He has told certain people at his workplace, such as his boss, about the hepatitis c. His boss is supportive if S is ill he would give S time off. However, there are many other people at S workplace who do not know anything about the hepatitis C because S has chosen not to tell them Being infected with hepatitis C means that S has been unable to get a mortgage, life insurance or holiday insurance. GRO-B has had to get a mortgage herself S does not have life insurance because it would be extortionate. He gets holiday insurance through the Haemophilia Society. All these issues get him down because no one entertains him as soon he mentions that he has hepatitis C.

S has medical records at home. He gets letters every few months and there are liver function test results contained in the documents. When I look at these test results they mean nothing to me they are all just numbers and I don't understand them. I do know that S doctor and his employers knew that S had Hepatitis C before S found out himself. The reason for this is when S was 18 years of age he applied for a job GRO-B GRO-B. As part of the recruitment process he agreed that his employers could have access to his medical records. S discovered he had Hepatitis C when he was 21 years of age. He requested a copy of his medical records and he discovered that his GP and his employers were aware that he had Hepatitis C before he himself had been informed. He discovered that parts of his medical records had gone missing. He was told that the parts of his medical records that are missing were destroyed and I think that is maybe because they contained notes about being infected which were never disclosed. It is not just S medical records that are missing, medical records to do with all the haemophiliacs that received treatment at Yorkhill Hospital are missing. The people responsible just say that they cannot give these documents to the patients because they are missing. I would like the inquiry to look into this and discover what happened to the documents of my son and others.

Section 6. Treatment/Care/Support

32. I am not sure of whether or not we were offered care and support in consequence of S being infected with hepatitis C. I cannot actually think of anything that we were offered. At the beginning S had liver scans once or twice a year, but these scans stopped when the doctors considered that they were no longer useful and that the only way to really tell how S liver was progressing was through a biopsy. However, S could not have a biopsy due to the risk of internal bleeding. The doctors now simply give S blood tests. He was up at the Haemophilia Unit last week to check that everything was alright. He is going through a period of bad stress just now, because his attendance and mobility allowances might be taken away or reduced.

33. S was offered counselling but chose not to take it because he was too depressed to speak to anyone when he was first told about the hepatitis C. Counselling was never made available to myself. It was Professor Lowe who worked in the haemophilia Department at the Royal Infirmary Glasgow who offered S the counselling.

Section 7. Financial Assistance

34. S receives an attendance allowance, but that is not related to his Hepatitis C, but to his haemophilia. When he was a child I received this allowance on his behalf. I started receiving it from S being two years of age. At that time I received £3 a week but obviously over the years that increased. I stopped receiving the allowance when S was 16 years of age and at that time I received approximately £30 a week. S then received this allowance in his own right. He did apply to the Caxton Charity and might have received a payment from them. He gets mobility allowance for his car and works full time. Further, he is entitled to PIP. I believe he get these allowances from the Department of Work and Pensions. I have no idea how much he receives. There have recently been discussions about taking his mobility benefit away, although he still needs

this. GRO-B needs the car to take him to and from hospital, especially if an emergency situation arises.

35. I don't know when and how S found out that financial assistance was available. I do know that he received assistance from the Caxton Fund a number of years ago. This was a one off payment. I do not know how much he received but at the time his gums were bleeding and he had stained his bed and bedding. With the money he received he was able to buy new bedding and a new mattress.

36. Many years ago, the government gave S an ex-gratia payment because he was infected with hepatitis C, although they never acknowledged that it was their fault. S GRO-B used this money as a deposit to buy their home. This will have been in 2006 as it was not long before his father died. I believe it was for £20,000.

37. I don't know much about the process of applying for financial assistance. S goes to all the haemophilia meetings and I am sure that is how he found out how to apply.

38. I don't think that S had any difficulties or obstacles when applying for and obtaining financial assistance. He just had to give a full account of his health. He still feels that this is some sort of "means test" and he has to account for every penny that he has whereas people who have never worked are getting all the benefits.

39. I don't know if any preconditions were imposed on the making of an application for the grant of financial assistance. I don't know enough about the process.

40. I feel sad that S is going through this situation regarding his car benefits being taken away because his car takes him to work and hospital appointments. It is very stressful for him and he thinks that the government is covering things up. The government will not admit fault and S has five years of medical notes missing and nobody will take responsibility for that. The notes missing relate to the period between 1979 and 1984. Maybe that is when he became infected.

I have not received any financial assistance from any of the Trusts and Funds set up to distribute payments. I only received attendance allowance to look after S when he was two years old from the DWP. I received this until S was sixteen and then it was transferred to him because he was classed as an adult. His wife administers the injections and provides all the help and support now.

Section 8. Other Issues

41. There are other issues that I believe will be relevant to the Inquiry's investigation and I would like to discuss. Before S was born, I worked for the Blood Transfusion Service. We used to ask questions to donors and depending on the answer the blood was taken or not. We were always closed for the Glasgow Fair Holiday. The Glasgow Fair Holiday used to last for two weeks and it was then that we collected blood from prisons, such as Barlinnie. Prisoners were told that they would be given a cigarette and sugar if they gave a pint of blood. We would ask the prisoners the same questions that we would ask everyone else. The prisoners would all deny having infections or diseases and we would then take the blood. If somebody was sick, their blood was for research and would not be used for transfusions. This was often the case when someone had jaundice. However, I remember that the two containers where we put healthy and infected blood were not differentiated and I wondered how they would know which blood was infected. Apart from that, the blood might or might not have been tested, we just had to take people's word for it when they told us that they were free from drugs and disease. I know that this practice continued until well after S was born because I kept in touch with the girls from work and they told me. The prisoners were not really given a cigarette and sugar in exchange for donating blood. They were just given a cup of tea and a piece of chocolate. I wonder how wide spread this practice was and what happened after we sent the blood away. The blood was sent to the blood bank at Low Hospital, Glasgow.

42. I have never taken the matter of S infection with hepatitis C to court. I do think that it is important for the government to admit that they were at fault for infecting patients with hepatitis C and that this is a matter which they knew about for years but did not tell

the patients until much later [redacted] tried along with the Haemophilia Group to take the American Company that provided the infected blood to Court, but it fell through and nothing ever came of it. This must have been about twenty years ago and the Haemophilia Group had lawyers representing their interests and would receive letters periodically.

Statement of Truth

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

Signed GRO-B

Dated 10-DEC-2018