Witness Name: GRO-B
Statement No.: WITN2152001
Exhibits: None
Dated: 13th 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 5th 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 1953. I am GRO-B: S GRO-B s father. I intend to speak about my son's experience of being infected with 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 family life.

2. My son S was born on GRO-B 1981 and I believe that he was infected with hepatitis C in July 1983, when he first received factor 8. S has Von Willebrand's disease.

Section 2. How Affected

3. The first time that my son S was at hospital and received treatment was in July 1983, after falling down GRO-B GRO-B at the time and it was the first time that we realised that he had a bleeding problem. He also received a blood transfusion on 16th July. GRO-B GRO-B. He fell GRO-B and sustained a cut to his lip, which caused a mouth bleed . It kept oozing and it didn't heal completely. This happened approximately 2 weeks before. On Sunday 10th July 1983 we went to visit my mother in law GRO-B and we took S to A&E at GRO-B which was only 5 minutes away. His mouth had started to bleed again. However, he did not receive any treatment on that occasion, other than we think some adrenaline. They were, like us, not aware of any issues with his blood. At some point afterwards, we attended GRO-B . I think he got sutures. He was kept in and the doctor thought he had problems with his platelets. This means that there was an issue with the make-up of his blood and this could cause problems with clotting. My wife and S were transferred by ambulance to Edinburgh Royal on 15th July 1983 and later that day to the GRO-B Hospital in Edinburgh. My wife thought initially that blood clotting factor was given for the first time that day at Edinburgh Royal Infirmary. However she now feels she is probably wrong due to medical notes on his hospital records she recently found. The following day he was given a blood transfusion at the GRO-B. I brought them home on the 17th July. On 19th July S's mouth started bleeding and we had to take him to GRO-B and from there he and my wife were again transferred to Edinburgh GRO-B GRO-B by ambulance. He definitely got treatment of clotting factors this time. They thought he had Haemophilia and were treating him for it. Since factor 8 hadn't stopped the bleed completely, still oozing, he got other treatments. They did further tests to discover why the treatment had been unsuccessful and discovered that S actually had Von Willebrand's disease. He had been given the wrong treatment and for this reason we decided to pursue a ical negligence claim, after we were told he had Hep C ,but it

never came to anything. The treatment for haemophilia that was mistakenly given to him increased his chances of being infected, although there would certainly still have been a chance that he would have been infected even with the Von Willebrand's treatment. The reason why I am saying this is that there are fewer donors for Von Willebrand's than there are for haemophilia, but there is still a chance.

4. S's Von Willebrand's disease is severe. It has been diagnosed as severe and S will never grow out of it. Due to Von Willebrand S has been in hospital many times, and he has experienced life-threatening situations. This has happened in the past and will continue to happen in the future. GRO-B GRO-B GRO-B and his clotting levels were very low. This was on Tuesday 2nd October. It really was a freak accident, he bumped the back of his head and this resulted in a GRO-B GRO-B He was taken to hospital on 3rd October 1984. We went with him to the Royal Infirmary in Edinburgh after our GP phoned an ambulance. He was in intensive care for one or two days. When he was younger, there were many trips to hospital whenever he had a bleed. Growing up, deep cuts or trauma and he experienced 2 unexplained gastrointestinal bleeds. Von Willebrand's is different from haemophilia in that it required a different clotting agent and at the moment he does not receive a recombinant like many haemophiliacs do. This is something that he might receive in the future but at the moment Edinburgh Royal Infirmary don't use it for anyone with Von Willebrand's. Any human plasma has the risk of transmitting mad cow disease because there is no test that can detect that and the doctors would only be able to find out once a donor has died. There is also a worry about the blood products that S has received. Our philosophy is that prevention is better than cure. E.G. - S doesn't use sharp knives, he doesn't use the lawn mower or any sharp garden equipment and he doesn't peel potatoes. He GRO-B has become more independent.

5. I don't know the exact names of any blood products that S received other than factor 8 but my wife has them in her statement. I would have to check the medical records in order to find out. I know that S received clotting products derived from human plasma. When he was treated for haemophilia, S received factor 8, but the first treatment that he received didn't work , because he didn't receive the right clotting agents in it to treat his Von Willebrand's disease.

6. S's first clotting factor was administered in July 1983. Professor Ludlam was in charge of haemophiliacs and other bleeding disorders at Edinburgh Royal. Dr Eden was the haematologist at the GRO-B Hospital. Whenever S had any check-ups it was Professor Ludlam who saw him when he was younger and when he sustained GRO-B bleeding, Professor Ludlam visited him in the GRO-B and appeared to be in charge overall. Other doctors who treated S were Dr Hoyle, Dr Rosie Dennis and Professor Hayes, the liver specialist. S was under the care of Professor Hayes when he first found out about his hepatitis C. S also had an operation in the Western Hospital, but this will be in his records. GRO-B GRO-B The nurses administered treatment of blood products some of the time. When he was older Dr Dennis saw S during his check-ups and whenever any problems arose, including his gastrointestinal bleeds. S is still treated at the Royal Infirmary in Edinburgh and his current doctor had nothing to do with S's previous treatment. He is Dr Ryan Rodgers. He is young and was still at school when all this happened. S and my wife really like him and respect him.

7. I believe that S was first infected in July 1983. We couldn't know that he was infected for a period of time. We have many volumes of medical records and it is impossible to find out when exactly he was infected because we are overwhelmed with paperwork containing a lot of very technical medical information that is not easy to read through and understand.

8. No information was given to us beforehand about the risk of S being exposed to infection or becoming infected. It was a completely uninformed decision. If we had known, we might have thought twice. We were also never told to take any precautions when dealing with S's blood. After the treatments, it was all played down and we were told that "non A/non B" was nothing to worry about. Hepatitis C was not called hepatitis C back then and we did not know that there was a risk of being exposed to AIDS as well. We were all tested for this. Luckily, we didn't have it. We got the feeling that they knew well before they told us as they were constantly testing S's blood. We were all tested for AIDS but were never offered a test for hepatitis C. My wife got a test a few years ago. She asked for it.

9. As far as we know, S is only infected with Hepatitis C and not any other viruses, but then again we have been warned about a risk of the mad cow disease, and this cannot be tested for so it's impossible to know until the infected person dies.

10. The first time that S was told that he had hepatitis C, my wife was not present because she was working. Only S and I attended the appointment. We found out that he was infected with hepatitis C in the early nineties. We received a letter asking us to bring S to meet with Dr Hayes and it mentioned liver problems. S was to be seen by Dr Hayes on 3rd February 1994. They don't mention hepatitis C in that letter, but it does say "as you know, some individuals with haemophilia may have liver problems" when the truth is that we didn't know about this because we had never been told whether or not haemophiliacs had liver problems and we had definitely never been told about hepatitis C or tested for it. At the time of the appointment, I was told that S's liver function was abnormal and treatment was offered. My wife only found out when I came home and told her. She was not happy and wanted a second appointment. My wife and I were alarmed.

11. At the first appointment I don't recall a discussion about the fact that others could become/be infected and I didn't even think at that point about the stigma

that would be connected to it. We had our second meeting on 29th March 1994. We were informed S would have acquired the virus prior to 1985 and liver tests indicated mild ongoing hepatitis. We consented to S being treated with Interferon.

12. I don't think they gave us any information to manage the infection. We had I believe to find out on our own. Ask questions. I really cannot remember being given any information. I believe my wife got information from the liver trust.

13. I think that information should have been given to us when he first received treatment. In particular, at the time of administering the treatment we should have been warned of the risks and we weren't. They knew about the infection before we were told. They knew that S had hepatitis non A/non B and I am sure that days after the treatment they must have known that something was wrong.

14. Blood came from prisons including American prisons, where donors included drug addicts and prostitutes. The Prison Governors, the drug companies and the blood transfusion service were surely making/saving money out of this.

15. According to the letter it was assumed we knew about liver problems , when we didn't. The first letter that we received asking us to bring S to the liver clinic in 1994 also didn't sound all that urgent. We were not pressed to make an appointment, and the appointment could always be rescheduled if it didn't suit us. We should have been told long before we were because I think that they knew a long time before they told us. They knew that something was wrong because they were continuously checking S's liver function. wonder how much longer they would have kept this information from us.

16. We were I believe not told about the risks of others becoming infected as a result of S's infection. My wife was probably the one who mentioned it to them. We were only provided with information about treatment and Hep C and the liver S didn't have a biopsy because it can be dangerous for those with bleeding disorders and it is the only 100% way to be sure if/how the liver has

been affected. My wife could have been easily infected because she was always involved with S's bleeds and that is why she got tested.

Section 3. Other Infections

17. S is at high risk of mad cow disease because of having received blood products, but there is no indication that he actually has had blood from a donor who has been diagnosed with it.

Section 4. Consent

18. I believe that S was treated or tested without our knowledge, without our consent and without being given adequate or full information. The reason why I say this is because we put our trust in the doctors as any parent would do, but we were not told that there were risk so we could not give our informed consent to the treatment.

19. I don't know whether S was actually treated or tested for the purposes of research, but it could be possible, I would not put it past them.

Section 5. Impact

20. Being infected with hepatitis C has had an impact on S and on us.

21. It is difficult to know whether or not S's GRO-B GRO-B When he was 13 years old, we told him that no one should touch his blood, but we tried to keep the hepatitis C from him. He just didn't understand. I think that if he hadn't had the brain haemorrhage he would have been a clever person S still doesn't understand his condition GRO-B GRO-B

22. The doctors don't think that S's liver has been affected as a result of the infection, although they cannot be sure without a biopsy, which S cannot have. Scans were satisfactory. His spleen is on the large side, but it is still within normal range. He was given a scan last year to check his spleen and might be given another one at a later date. GRO-B GRO-B As he has become older, it has been a concern that when/if he has a partner he has to tell them about the hepatitis C. We have requested yearly tests for S. Despite the virus now having been cleared (this only happened two years ago) we feel it is too early to be completely sure and the virus could be dormant and then re-appear. There is a stigma about it and only close friends and family know. S attends the psychologist at the Haemophilia Centre in Edinburgh. My wife suffers badly from anxiety and also attends.

23. S never really showed symptoms of hepatitis C. We were told that it was dormant and that it could take twenty years to manifest. We thought about whether we should put it out of our minds for twenty years and only then start worrying. However, then something in the news would come up and we would worry. We tried to keep as much from S as we possibly could and it has affected us psychologically. There are many symptoms that a person with hepatitis C can get and it would be hard to tell whether or not they are related to the condition.

24. S was given Interferon, which did not work for him. The injections were administered at the GP clinic and they were very sore. He had side effects from them. He had fever after the first dose and then had aches and pains after two weeks on the treatment. In another 4 weeks, he was not tolerating the treatment well . He received this first treatment at the end of March 1994. Then, he went through another treatment. He developed photophobia, vomited and developed migraines. He had less energy than when he first started the treatment and a lot less energy than usual. The injections were really large and he received them for 21 weeks. It was reported that he was

not responding well to Interferon and that he should stop the treatment. His second course of treatment was Interferon and Ribovarin. This time around, my wife had to give him the injections and they were very sore. The injections were administered to his tummy. She did it several days a week, and it didn't work either. This second course of treatment took place a few years after the first treatment. It was traumatic, although it didn't last as long as six months. Some people felt that six months was not long enough. However, he didn't respond to the treatment and it was unsuccessful. The side effects were horrible too. It was a very painful experience that came with negative psychological effects. GRO-B S GRO-B GRO-B GRO-B GRO-B S felt great for the first few weeks of his treatment and then he became completely emotionless. He had a lot of problems with anxiety and frustration and anger. He is supposedly cured, but we have asked for repeat blood tests and will continue to ask for them on a yearly basis because we feel it's too early. His last treatment was called Harvoni and it was in tablet form S took this early in the morning with his regular medication for acid . He reacted well to Harvoni very quickly. Professor Hayes would have expected this and it was normal. The medical profession concentrate on hepatitis C mainly with the liver, but it can also affect other organs. The stigma around it is horrendous and it is upsetting to talk about what happened. Also it makes us angry.

25. We had access to the new treatment because we heard about it on TV and my wife contacted Professor Hayes to ask about it . He had the year before spoken to her about a new cure . He was hoping that haemophiliacs would be given access to the treatment as soon as possible, but was unsure as to what the pecking order would be. GRO-B GRO-B S GRO-B GRO-B

26. It is hard to know whether treatments were available that were not offered. They should have maybe given earlier treatments for longer periods of time.

S has type 3 hepatitis C and this is the hardest one to cure. However, Harvoni was specifically for hepatitis C whereas the other treatments such as Interferon were only administered to see if they could help. If Harvoni hadn't worked, S would not have gone through any more treatments. He told us that this was his decision.

27. We feel as a result of his treatments, S feels the cold a lot and goes to the toilet a lot. He has had problems with his skin. He developed folliculitis and was on antibiotics for a long while. He also suffers from dry eyes. I don't think that he is currently experiencing any other complications from his treatments, and we have already discussed the ones that he experienced while he was on each of the treatments.

28. S has issues with access to dental treatment as do many other people with bleeding disorders. The community dentist is only ever allowed to conduct an inspection. If any bleeding is expected, S has to attend the Royal Infirmary in Edinburgh. At least, that is the way it used to be. I do not know if this has changed over the years. There is also no problem with the local dentist doing a small filling where no drilling is needed and no other medical practitioners have refused to treat him because of his hepatitis C. He always goes to the Royal Infirmary if bleeding is involved.

29. S being infected with hepatitis C has had an impact on his and on our private, family and social life. Growing up, S was not able to take part in many activities because of his Von Willebrand's. However, you still had to let your child be a child and that meant dealing with bleeds and bloodstains. Someone could have contracted the infection from S Then you had to watch that S wouldn't get involved in activities where he could get hurt and infect someone else GRO-B he sometimes had some blood on his lips while clotting took place. S GRO-B GRO-B GRO-B We try and give him life experiences that he wouldn't otherwise have. GRO-B. He has problems

with his relationship with the opposite sex. He has been out for lunch with women, but he has never had any sexual contact. However, if he does meet a sexual partner, then his hepatitis C will be an issue. If it wasn't for GRO-B GRO-B he could have been in a relationship. We believe that because of his GRO-B, he has been affected in his development. He doesn't have a clear understanding of hepatitis C. He has not had a normal life . When he had a bleed, we would try and keep an eye on him, and keep him aware. He takes Cyklokapron to help clotting of minor mouth bleeds. This is not made from plasma, but is a manufactured product. He has had no treatment for his Von Willebrand's in years. We have always taken his medication with us whenever we have been on a holiday abroad together. This includes clotting products from blood .The new product is used worldwide and I think that it must be safer. GRO-B GRO-B We have to provide medical letters to account for the medical equipment and medication that we take with us. We tend to do it ourselves because S would get anxious if asked questions from airport security and border controls, when declaring blood products. Needles and syringes are also included. He still has to disclose that he has hepatitis C for travel insurance purposes.

30. I feel that there is a stigma attached to hepatitis C, especially when getting life insurance. It has affected us terribly. We are constantly worrying that he might have passed the hepatitis C to someone else or even to ourselves. Only our close friends know and I don't even know if S's friends know. Now people are more aware that you have to wear gloves when handling blood. On top of that, when your baby falls down you don't even think about gloves, you just want to see that he is alright. I think once a hospital doctor GRO-B GRO-B kept cleaning his bleeding knee rather than applying pressure. My wife had to intervene. Hepatitis C is something you don't talk about and you try and avoid conversations where it might come up. It is not the sort of thing that you would have disclosed to people in the old days. It was very much like the stigma of having AIDS. There is no closure and you don't know if there will ever be.

31. S's school performance and choice of career would have been different if he hadn't had all these health issues, but this could have been due to the brain haemorrhage as much as to the hepatitis C. We believe that it was mainly the GRO-B which affected his performance. GRO-B GRO-B Hepatitis C treatment increased his mood swings. Without all these health issues, he would have attended GRO-B and maybe university. He was depressed at times and he was angry about having hepatitis C. It is unknown how much of a part hepatitis C has played in interfering with his normal development. The stigma and public perception of hepatitis C made things worse for S because he didn't understand. We didn't have to give up work because of S's condition.

Section 6. Treatment/Care/Support

32. Care, support and counselling were never offered as a result of S becoming infected with hepatitis C. My wife and S told their current psychologist that they could have used some support 20 years ago. They were not referred to this psychologist through the NHS, but through the Haemophilia Centre, because of S This counselling was offered to everyone in the family, but I chose not to take it.

Section 7. Financial Assistance

33. S has received some form of assistance from the Trusts and Funds set up to distribute payments.

34. Bill Wright from Haemophilia Scotland told us about S's entitlement to financial assistance and so did Tommy Leggate from SIBF. They were here and spoke about it. S had his benefits stopped and applied for financial assistance. My wife had to fill in forms for the Scottish Government, who will

make annual payments to be received on a monthly basis just the other day and we don't know how much these payments will amount to.(s now receives these payments.)

35. s received £20,000 from the Skipton Fund initially. This was years ago. In the last few years s received £30,000. This was paid by the SIBSS. He also got £1,000 a year from them, but only got it for the first time last year because we didn't know about it any sooner s never got anything from the Caxton Fund.

36. The process of applying for financial assistance is filling in forms and sending them. My wife filled in all the forms.

37. We applied for financial assistance to see if they would help with a fault in s s shower, but we were turned down s receives no heating allowance. We thought that he would receive £1,000 towards heating, but the £1,000 that he currently receives is not solely linked to heating. We pay for his electricity bills. Further, they are not able to backdate the £1,000 payments that he missed. At some point, s may have required a top-up to bring GRO-B up to the minimum, but he wouldn't qualify for one as he is now back on his benefits.

38. The £1,000/year payment that he received is not means-tested or offset against any benefits. The payments that are now being paid made by the Scottish Government are not means-tested either. There were no preconditions, but criteria apply that are specifically associated with hepatitis C.

39. My opinion about financial assistance is that the system in place makes people feel like they are begging for help when we didn't ask for s to get hepatitis C. The establishment is to blame and many people have lost their lives while others are still fighting. The Scottish Government have done more than any other Government. It is the UK Government, under Margaret

Thatcher and subsequent prime ministers that have swept everything under the carpet. The results of the Penrose Inquiry were very disappointing.

40. I have not received any payments from any of the Funds or Trusts and have never applied for them.

Section 8. Other Issues

41. We have been in the past involved in litigation about S being given the wrong treatment for his Von Willebrand's disease. This was with a firm from Edinburgh called GRO-B. S got legal aid to pursue this claim, but the claim never went anywhere. Another firm, GRO-B, helped us obtain the first £20,000 from the Skipton Fund. We were never involved in the Penrose Inquiry. Although my wife may have submitted S's story. We are involved with the Scottish Infected Blood Forum and with Haemophilia Scotland. My wife campaigns by visiting MPs and writing letters, she can be quite vocal. I come along, but don't do as much campaigning. We only started going a few years ago, I can't remember when. We attended meetings when S was in his teens after being told of his Hep C virus.

42. Documents that are relevant for the purposes of the Inquiry would be the ones that my wife has pointed out from the medical records. Some others could also be important, but they are very technical and we don't even know what some things mean, plus the medical records are vast in number. Some are faded and some are illegible. My diaries from 1983 and 1984 were helpful. The fact that liver function tests are referred to and that hepatitis non A/non B is mentioned proves that they were aware of infected blood being used.

Statement of Truth

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

Signed GRO-B

Dated 23/2/19