Witness Name: GRO-B
Statement No.: WITN2151001
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 1950. I am GRO-B: S S's mother. 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 first infected with hepatitis C in GRO-B 983, when he first received clotting factor 8.

S has severe Von Willebrand's disease, a blood clotting disorder. In the same month he also received a blood transfusion .

Section 2. How Affected

3. The first time that S received treatment was in GRO-B 1983, after falling down GRO-B This took place roughly 2 weeks beforehand. He was aged GRO-B and it was the first time we realised he had a bleeding problem. GRO-B he had cut his lip, which caused a mouth bleed that wouldn't stop completely. It kept oozing blood . A few days after the injury, on Sunday 10th GRO-B 983, while visiting my mother we took S to A&E at the local hospital as bleeding had started again. I am sure he received some adrenaline . GRO-B GRO-B They were like us unaware of any issues with S's blood. On 13th GRO-B profuse bleeding at 4am in the morning resulted in an immediate visit to the local hospital. We took S to GRO-B Hospital. I think they applied stitches. He was admitted and after some tests we were told that S had a problem with his platelets. This means that there was an issue with the make-up of his blood and this caused problems with clotting. The haematologist arranged for S to be taken to the Royal Infirmary Edinburgh. On Friday 15th GRO-B 1983 I accompanied S and we travelled by ambulance complete with siren. That day I thought he received factor V111 for the first time. I really thought that this was when he was first infected. But looking at a copy of S's medical records. I have found an entry in handwritten notes dated 9th GRO-B 1983 which reads "Blood at RIE by Dr Tucker then to RHSC." This has made me unsure. I am not certain what this means. (I cannot find any record for GRO-B 15th clarifying what happened at the Royal infirmary. Also there are no records from GRO-B Hospital. It closed down years ago.) I assume it meant bloods taken by Dr Tucker. The same day he was admitted to GRO-B Hospital and on the 16th GRO-B he was given a blood transfusion. He was discharged on 17th GRO-B Unfortunately he injured his lip again and at 2 am on 20th GRO-B we had to take him to hospital in GRO-B

As I recall they found it difficult to treat him as he was so upset .We could hear him crying and we were very distressed. He was just a toddler and they were having a problem treating him . He again was admitted to GRO-B The same day he received 250 units of Factor V111i.v. Next morning his mouth was still oozing S was given DDAVP (0.36 mgs Iv.) there was still a slight oozing and he was given one bag of cryoprecipitate I.V. They did further tests at Edinburgh Royal and S was diagnosed as having Von Willebrand's They had been treating him for haemophilia . He had been given the wrong treatment. Although factor 8 is used to treat both haemophilia and Von Willebrand's there are different blood components added for each of these conditions. In later years after being told S had Hep C we decided to pursue a medical negligence claim, but it never came to anything. It went as far as obtaining a report from a professor in England who said treatment did not amount to negligence although he had been given the wrong treatment. This had greatly increased his chances of being infected, although there was still a risk of infection with the Von Willebrand's treatment. The reason why I am saying this is that there were fewer plasma donors required for Von Willebrand's treatment than for haemophilia .Many more donors are required for haemophilia. A young registrar, Dr GRO-B at the GRO-B Hospital GRO-B GRO-B Edinburgh told me this and that the ratio was 12 or so compared to say 100 plus donors.

4. I think that I might have had Von Willebrand's because I nearly haemorrhaged when I gave birth to S. You can grow out of mild or moderate Von Willebrand's, but not severe which S has. There was no history in the family of this.

5. 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, S has been in hospital many times, and he has experienced life-threatening situations. This has happened in the past and could happen in the future GRO-B GRO-B GRO-B GRO-B his clotting levels were

very low. This was on Tuesday 2nd October 1984. It really was a freak accident, he bumped the back of his head and this resulted in GRO-B GRO-B He was taken to hospital on 3rd October 1984, We went with him to the Royal Infirmary in Edinburgh after the GP phoned an ambulance. He said it was an ambulance situation . He believed S was bleeding internally. Unfortunately when it arrived it was filled with adults going to various outpatient clinics at the Western and the Royal. The driver went quite slowly as I recall. We were the last to be dropped off. He was in intensive care for one or two days. He was given 360 units of .factor V111. He also had intensive cryoprecipitate between 3rd October and 18th Oct - 34 units in total.. When he was younger, there were many trips to hospital whenever he sustained an injury and even now there is a risk. We look on prevention today as being better than the cure owing to risk of CJD or any new viruses which could develop. Growing up, deep cuts or trauma could be life-threatening and he has twice experienced unexplained gastrointestinal bleeds In 2007 and in 2014. Von Willebrand's is different from haemophilia in that it requires a different clotting component and at the moment he does not receive a recombinant factor 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 from the UK has the risk of transmitting mad cow disease because there is no test that can detect it and the doctors would only be able to find out once a person dies. There is also a worry about the blood products that S has already received. Our philosophy is that prevention is better than the cure Examples - 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. S has received since diagnosis, treatments such as Haemate P , factor 8 and cryoprecipitate. I cannot be sure of exact dates other than already stated without careful analysis of medical records. I know tha S received clotting products derived from human plasma. When he was treated for haemophilia, S received factor 8. This treatment didn't work for him because he didn't receive the right clotting agent in it to treat his Von Willebrand's disease.

6. S's first clotting factor I originally thought was administered on his first visit to Edinburgh Royal Infirmary on GRO-B 15th 1983. However on examining copies of handwritten notes on S's medical records (an entry dated 9th GRO-B 1983) it would appear that only blood samples were taken that day at Royal Infirmary. I cannot find notes written on 15th GRO-B Since it is over 35 years, I seem to have been mistaken. Professor Ludlam was in charge of Haematology at Edinburgh Royal. Dr GRO-B was his consultant at GRO-B GRO-B although Professor Ludlam appeared to be in charge overall. When S had any check-up appointments it was I recall Professor Ludlam who saw him especially when he was younger and he also visited him once at GRO-B GRO-B GRO-B He decided on how long S should stay in hospital. Other doctors that S saw that I remember were Dr GRO-B registrar GRO-B Dr Rosie Dennis and Professor Hayes. Others I don't remember. S was under the care of Professor Hayes , the liver specialist, when we first found out about his hepatitis C. S also had an operation in the Western General Hospital Edinburgh in 2001 for a GRO-B The nurses administered S's treatment most of the time. In latter years Dr Rosie Dennis was S's haematologist during his check-ups and was always on the other end of the phone if there were any problems. S is still an out patient at the Royal Infirmary in Edinburgh and his current consultant is Dr Ryan Rodgers, with whom we have built a good relationship since Dr Dennis retired. S has never required treatment as yet while under him. He is only in his thirties but we greatly respect him.

7. I believe that S was first infected in GRO-B 1983. We didn't know that he was infected for years. 1994 to be exact. 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. Also handwritten

notes are hard to read and some earlier copies of records are faded or distorted. He was definitely infected before 1985 and this has been recorded in his medical records. I am sure he was infected in GRO-B 1983. He may have been infected on more than one occasion.

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 would have thought twice. We were also never told to take any precautions when dealing with S's blood. After the treatment had begun I was told by Dr GRO-B registrar at GRO-B that fewer donors were required for Von Willebrand's so there was less risk of infection. I questioned this and am sure that is when non A, non B was first mentioned. It was always played down . We were never informed that S had contracted Non A - Non B which was nothing to worry about we were led to believe. 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. I/we really feel that they knew well before they told us as they carried out many blood tests. There was an instance when I was unwilling for S to receive treatment of blood clotting products following a tooth extraction on 24th August 1993 because I was worried about the risk of AIDS and Dr Ludlam was contacted to persuade me. At this point he came to speak to me and told me that the blood products were safer as they were now heat treated. I am positive that they knew for a very, ,very long time that S had hepatitis C, but never told us. I found a copy of a letter in his medical records which mentioned that I had allowed treatment and that they could not give me 100% assurance that the blood product (Haemate P) administered to S that day was 100% safe. This was prior to being told about hepatitis C. I was so worried about S contracting Aids. Yet they were I am positive hiding the truth about him and all the others being infected with Hep C. This has made me so angry. Virology was if I recall mentioned in S's medical records when blood was taken for testing. We were unaware of this at the time. We were all tested for AIDS but were never offered a test for hepatitis C. I requested a test a few years ago.

9. As far as we know, S is only infected with Hepatitis C and not any other virus, 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 a donor dies.

10. The first time that S was told that he had hepatitis C, I was not present because I was working. Only S and my husband attended the appointment. We found out that he was infected with hepatitis C on March 1st 1994. We received a letter from Professor Ludlam dated 3rd February 1994 asking us to bring S to the liver clinic and advising S was to be seen by Dr Hayes now Professor Hayes on March 1st. He didn't mention hepatitis C in that letter, but it read "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 that haemophiliacs or others like S may have liver problems and we had definitely never been told about hepatitis C or tested for it. At the time of the appointment, my husband was told that S's liver function was abnormal and treatment was offered. I only found out when my husband came home and told me. I was not happy and extremely worried and anxious. I attended a second appointment on 29th March 1994 . I was very unhappy and felt very uncomfortable during the appointment. On this occasion when I came out from seeing Professor Hayes and Professor Ludlam, I told a nurse that I objected to the presence of foreign students while hepatitis C was being discussed as this information was too sensitive and I was trying to process all the conversation. They were virtually glaring at the three of us. However, I have to say that Professor Hayes was very nice . He had no responsibility for S's Von Willebrand's treatment. We were informed on 29th March that S had contracted Hep C prior to 1985.

11. We had our second meeting on 29th March 1994. We were told S would have contracted the virus prior to 1985 and liver tests indicated mild ongoing hepatitis. We consented to S being treated with Interferon.

12. I can't remember being offered information to manage the infection. I think we had to find out or ask questions on our own. I really cannot remember being given any information.

13. Information should have been given to us earlier. In particular, at the time of administering the treatment we should have been warned of the risks and we weren't. I was even washing S's blood stained clothes in the bath at the GRO-B Hospital and Dr GRO-B was helping me. Neither of us had any plastic gloves on. They knew about the infection before we were told. They must have known that S had hepatitis non A/non B and I wouldn't be surprised if they knew this shortly after treatment in 1983/1984. In fact they knew there was a high risk of blood being contaminated before it was even used.

14. Blood came from prisons including American prisons, where blood was obtained from drug addicts and prostitutes. The Prison Governors and the drug companies and the blood transfusion service were all making or saving money out of this and they knew where the blood was coming from. As did Government ministers. **We didn't know.** The first letter that we received asking us to bring S to the liver clinic on March 1st 1994 was dated 3rd February 1994 . It didn't sound all that urgent. We were not pressed to keep the 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 always checking S's liver function.. I wonder how much longer they would have kept this information from us if alarm hadn't been raised in other countries. Common sense tells you the perils of such a blood supply. Saving money more important than human life? Also giving such blood to a toddler is just so despicable .There is a strong chance S s treatment included blood taken from such sources

15. We were I believe not told about the risks of others becoming infected as a result o S's infection. I was probably the one who mentioned it to them. We

were only provided with some information about treatment and Hep C. s did not have a biopsy because to do a biopsy on any person with a bleeding disorder can be dangerous and that is the only 100% way to be sure how or if the liver has been affected. I could have been easily infected because I was always involved with s's bleeds and that is why I got tested. We might have received some literature on the infection, but the doctors played down the situation. I contacted the liver trust and they sent me literature on Hep C.

Section 3. Other Infections

16. s is at high risk for mad cow disease because of having received blood products, but there is no indication at present that he has had blood from someone with it..

Section 4. Consent

17. I believe that s was treated and tested without our knowledge of the risks. 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.

18. I don't know whether s was actually treated or tested for the purposes of research, but it is entirely possible. I would not put it past them.

Section 5. Impact

19. Being infected with hepatitis C has had an impact on s and on us.

20. It is difficult to know whether or not S 's GRO-B relate partly to hepatitis C but it may have contributed. 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 GRO-B GRO-B GRO-B S GRO-B GRO-B GRO-B I took all the worry upon myself and tried to keep as much as I could from him. although he still experienced a lot of mental anguish S still does not understand his bleeding condition far less the impacts of hepatitis c.

21. The doctors don't think that S 's liver has been affected as a result of the infection, although they cannot be 100% sure without a biopsy, as Professor Hayes informed me. This it is not advisable, due to bleeding risks. Liver scans were satisfactory. His spleen is on the large side but is within normal range for his stature. He was given a scan last year to check this and may receive another one in the future. GRO-B GRO-B As he has become older, it has been a concern and when or if he has a partner he will have to tell them about the hepatitis C. We have requested yearly tests for S . Despite the virus now having been cleared, so we are told. This only happened two years ago so it is too early to tell 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. I suffer badly from anxiety and also attend.

22. S we felt never really showed symptoms for hepatitis C. We were told that it was dormant and that it would 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. On reflection he probably was affected but we were only focusing on liver problems. It was never over the years out of my

thoughts. I was always worried. Every time S was unwell I would become so anxious thinking - is this the Hep C now taking a hold? There were so many media reports which were so frightening. One saying it was more dangerous for children infected. It was awful and I was beside myself with worry.

23. 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 which started in October 2003, was Interferon and Ribovarin. The latter must have been a powerful drug as we had to sign a form. It could affect babies in the womb and on conception. Patients were to refrain from any sexual contact. This time around, I had to give him the injections and they were very sore. The injections were administered into his tummy. I did it several days a week, and it didn't work either. It was traumatic, although it didn't last as long as six months. Some organisations felt treatment should have continued for longer periods. However, he didn't respond to the treatment. Again it was unsuccessful. The side effects were horrible too, it was a very painful experience that came with negative psychological effects. The last treatmen S 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 to be certain. His last treatment was called Harvoni and it

was in tablet form. S took this early in the morning and he reacted positively to it very quickly. Professor Hayes would have expected this as it was the norm for this drug. The medical profession mostly associate hepatitis C with the liver, but it can also affect other organs. The stigma around it is horrendous and every time you have to talk about it, it is so upsetting.

24. We had access to the new treatment because we heard about it on TV and contacted Professor Hayes to ask about it. He had spoken about excitement of a cure to us a year earlier. 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. He contacted GRO-B Health Board where it would be easier for S to go and get treatment so that he didn't have to wait too long. We pushed the matter as well.

25. It is hard to know whether treatments were available that were not offered. They should have maybe given the treatments for longer periods of time. I really don't know 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. When Harvoni was at an experimental stage it was not offered to S until it was licensed and available. Drug companies can delay licensing for power and money. Harvoni is supposed to be better because it has fewer side effects. If Harvoni hadn't worked, S would not have gone through any more treatments, he told me that was his decision. Having said this hep c may cause him physical problems in the future. As it could have affected other parts of his body. He definitely has been psychologically affected. As already documented Hep C could have an adverse affect on relationships with the opposite sex. This causes more psychological problems.

26. As a result of his treatments, I now feel they have contributed to S feeling the cold, frequent visits to the toilet and mood swings. He has had problems with his skin. Harvoni affected his emotions. 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.

27. 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 or a small filling which requires no injection or drilling. 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 don't think it has changed. No other medical practitioners have refused to treat him because of his hepatitis C as he always goes to the Royal Infirmary if any hospital treatment is required.

28. 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 injuries and washing bloodstains. Someone could have contracted the infection from S We had to watch that S wouldn't get involved in activities where he could get hurt and infect someone else. However, when we were unaware of hepatitis C, he sometimes had blood on his lips when a bleed was clotting. S still does a lot of things with us because of his problems. He goes on holiday with us. We try and give him life experience that he wouldn't otherwise have GRO-B 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 he could have had a partner. HOWEVER HEP C COULD JEOPARDISE A RELATIONSHIP AND THE DECISION TO HAVE A FAMILY. 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 kept an eye on him, and kept him aware of the importance of people not touching his blood. He takes Tranexamic Acid to help clotting. This is for minor mouth bleeds. This is not

made from plasma, but is a manufactured product in tablet form.. He has had no factor treatment for his Von Willebrand's in years. We take his medication/treatment with us when we go abroad on holiday. The new treatment is Voncenta and is used worldwide and I believe that it is safe! It is still from blood products. I believe it is manufactured elsewhere GRO-B GRO-B GRO-B We have to provide medical letters to account for the medical equipment and medication that we bring with us. We tend to carry it ourselves because S gets frustrated GRO-B It is daunting at customs and border controls. He still has to disclose that he has hepatitis C for travel insurance purposes. Also that he is at higher risk of CJD.

29. 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 remember once a hospital doctor in GRO-B tried to clean S s knee before stopping the bleeding, which is not advised and I 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 or even now. It was very much like the stigma of having AIDS. There is no closure and you don't know if there will ever be.

30. 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 GRO-B as much as to the hepatitis C. We believe that it was mainly the brain haemorrhage which affected his performance. GRO-B GRO-B Hepatitis C treatment gave him increased mood swings. Without all these health issues, GRO-B GRO-B 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. I started work when S GRO-B

Section 6. Treatment/Care/Support

31. Care, support and counselling were never offered until the last few years. As a result of S becoming infected with hepatitis C and having a bleeding disorder we are able to access a psychologist. We told the psychologist that we could have used support many years ago. We were not referred to this psychologist through our GP, but through self referral to the Haemophilia Centre. This counselling was offered to everyone in the family. The psychologist is aware of how it has affected us. Years ago, we had nothing like this. She is highly respected and liked by us all.

Section 7. Financial Assistance

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

33. 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. We had to fill in forms recently .for the Scottish Government, regarding annual payments to be received on a monthly basis and S now receives payment from them. It was backdated to September 2018. His benefits were reinstated by a second tribunal.

34. S received £20,000 from the Skipton Fund initially. This was years ago. In the last few years S has received £30,000. This happened maybe 2 or 3 years ago, but should have been paid a long time before. This was paid by

the SIBSS. He also got £1,000 a year from them, but only got it for the first time in 2017 because we didn't know about it S never got anything from the Caxton Fund.

35. The process of applying for financial assistance is filling in forms and sending them. I filled in all the forms and they required a lot of copies of bank statements so we had to obtain these.

36. We applied for financial assistance to see if they would help with a fault in S's shower, but we were turned down S received no heating allowance. We thought that he would receive £1,000 towards heating, but the £1,000 that he received was not solely linked to heating. At present we pay for his electricity bills. Further, they could not backdate £1,000 payments that he missed. At some point S may have required a top-up GRO-B to the minimum, but he wouldn't qualify for one as he is now back on benefits and is in receipt of payments from the Scottish Government..

37. The £1,000 a year payments that he received were not means-tested or offset against any benefits. The payments that have now been made by the Scottish Government are not means-tested either. There were no preconditions, but criteria apply that are specifically associated with hepatitis C. He now receives a monthly payment from the Scottish Government.

38. My opinion about financial assistance is that the system can make people feel like they are begging for help. 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, probably under Margaret Thatcher and subsequent prime ministers that swept everything under the carpet. The results of the Penrose Inquiry were very disappointing and a complete waste of money in my opinion.

39. I myself have not received any payments from any of the Funds or Trusts and have never applied for them. I would apply if such an opportunity arose as I have developed stress related IBS, a dry mouth and dry eyes as well as many psychological effects as a result of what happened to S I worried for years and still do about the infected blood ,how it has and still could affect S and the anxiety symptoms I have suffered for years.

Section 8. Other Issues

40. 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 GRO-B. As S was a minor we got legal aid to pursue this claim, but the claim never went anywhere. Another firm from GRO-B helped us obtain the first £20,000 from the Skipton Fund. We were never physically involved in the Penrose inquiry other than I believe submitting S's story. We are involved with the Scottish Infected Blood Forum and with Haemophilia Scotland. I campaign by visiting MP's, MSP's and writing letters, I can be quite vocal. My husband comes along, but doesn't do as much campaigning. We only started going a few years ago, I can't remember when. Although we attended meetings when S was a teenager and I spoke to MP's then as well. Some times in the past I had to distance myself from meetings in order to cope. They are very emotional gatherings.

41. Documents that are relevant for the purposes of the Inquiry would be the ones that I have pointed out from the medical records. Dates of treatments and exact treatments mentioned are taken from 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 of them are illegible and some are faded. 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. Also being told that Von Willebrand's treatment carried a lower

risk of infection. (Although still a risk). Consequences were played down. My husbands diaries from 1983 and 1984 were also helpful for dates.

Statement of Truth

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

Signed GRO-B

Dated 23/12/19