Witness Name: GRO-B
Statement No.: WITN2141001
Exhibits: None
Dated: 15th October 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 1st October 2018.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is name is GRO-B. My date of birth is GRO-B 1965 and my address is known to the Inquiry. I am currently divorced. GRO-B
GRO-B
GRO-B

2. I intend to speak about my experience of being infected with Hepatitis C. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my life to date.

Section 2. How Infected

3. I have Resus disease which is a disorder in which, when pregnant, there is a risk that antibodies in my blood will destroy the blood cells of my unborn child. I have required to have injections of medication called Anti-D immunoglobulin in order to treat this condition. I have RhD negative blood.

4. In order to treat my condition, I have received Anti-D immunoglobulin during my five pregnancies. GRO-B GRO-B I have given birth to my three children.

5. I was given Anti-D immunoglobulin at GRO-B in 1983 and once in 1984 at the GRO-B Glasgow. GRO-B GRO-B During my three pregnancies which ended with the birth of my three children I received Anti-D immunoglobulin and was under the care of the Queen Elizabeth Hospital, Glasgow in 1997, 2003 and 2005. GRO-B GRO-B

6. I believe I was infected either in 1983 or 1984 as I received Anti-D immunoglobulin at this time. I also received Anti-D immunoglobulin when I had my children in 1997, 2003 and 2005. I do not believe that I received the infection during 1997, 2003 or 2005. I explain why I think this below.

7. When I was really young (about 17 years old) I fell pregnant. GRO-B GRO-B

GRO-B I was given Anti-D immunoglobulin at that hospital. I remember at the time, the hospital said that this would happen because of my blood type. I know I have an entry in my GP medical records which confirms that I received Anti-D immunoglobulin at this time and at this hospital. I remember shortly after the termination I had a wedding to attend. I wasn't feeling well. I felt like I was coming down with a virus. I had a temperature and felt flu like. I remember I bought my friend plates and cups as a gift for her wedding. I remember I was having trouble carrying this gift because I wasn't feeling well and was very weak. I assumed I had a flu type virus but I now wonder if this is where I became infected.

8. I received more Anti-D immunoglobulin the following year when I was around 18 years old. I found out I was pregnant. I had to take the morning after pill. GRO-B GRO-B I was given Anti-D immunoglobulin as part of the process at that hospital. I wasn't feeling very well after this and I do wonder if this was the time I was infected or whether this was the second time of infection. I suppose I could have been exposed to the hepatitis C virus on both of these occasions.

9. I cannot be sure on what occasion I was infected but I believe it to be 1983 or 1984. I have learned through reading online that when I received Anti-D immunoglobulin during this period it was around the time before blood donations and products were not tested for Hepatitis C or heat treated. It makes me doubt that my Anti-D immunoglobulin was safe. I have never been able to have these points addressed. It makes me suspicious. I don't have any information about what batch number of the Anti-D immunoglobulin that I received on each occasion. I just have a letter from the GRO-B that tells me I received Anti-D immunoglobulin in 1983. I don't have a letter for 1984. I don't know if it was the GRO-B or GRO-B GRO-B where I received the infected Anti-D immunoglobulin but it was one of them. I have received Anti-D immunoglobulin automatically for all my pregnancies due to my

blood type. I did not feel unwell after the injections in 1997, 2003 or 2005 like I did in 1983 and 1984. I think I was infected in 1983 and/ or 1984.

10. I read about other countries that had had scandals with infected Anti-D immunoglobulin and I thought they sounded like my case. I knew I had received Anti-D immunoglobulin because I am blood type O negative. I am not an expert but I read a lot about Anti-D immunoglobulin from reading online. I remember I brought up Anti-D immunoglobulin with someone at a medical appointment and they said to me *"no Anti D is safe in this country".* To me that seems to be the official line as when I applied for support I was also told "*oh no Anti-D is safe*". I cannot remember who said this to me.

11. I received a letter from the Scottish National Blood Transfusion Service dated 27th February 2017. It had been sitting in a pile of letters for a couple of days because I am not very good at opening mail. I remember it was a Saturday morning which would have been the 4th March 2017 that I opened the letter. I was really shocked when I opened the letter. The letter said that whilst giving blood (around 10 years earlier) I had actually tested positive for some kind of blood borne infection. The letter didn't say what I tested positive for just that I was positive for some kind of blood infection. The letter asked me to make contact with a Scottish National Blood Transfusion Service doctor or nurse. The letter said that I could get more information from the Scottish National Blood Transfusion Service. It was a Saturday morning so I couldn't call anyone to discuss it. The phone lines were only open 9am to 4.30pm. I was worried about the letter as it didn't say what type of infection I was carrying. It was very stressful.

12. After reading the letter thoughts were going round and round my head. I remember thinking "*What is this?*" and "*could it be AIDS?*" I had to wait

through the weekend to speak with someone on the Monday as directed in the letter.

13. I remember I phoned the number in the letter on the Monday which would have been the 6th March 2017. The nurse I spoke to told me on the phone that I had tested positive for Hepatitis C. I cannot remember the name of the nurse. The nurse provided me with some information about the infection. I had no knowledge of Hepatitis C. I was relieved that it wasn't HIV or AIDS as that is the worst thing I could have been told. I remember I asked the nurse if my infection was serious and in what way it could be serious to my health. The nurse told me that Hepatitis C can damage the liver. The nurse gave me the name of a website where I could get more information and which was a general support website. I cannot remember the website as I have looked at so much online. The nurse told me that I would be referred to a consultant and I would get a letter through the post about an appointment with the consultant. That was the end of the phone call.

14. During the phone call on the 6th March 2017 the nurse said that the Scottish National Transfusion Service had sent me a letter after I had donated blood on the 5th November 2007. She said my GP would have got a copy. I had not received a letter. I was really shocked that nobody had contacted me in all those years. My GP didn't event contact me to tell me of my diagnosis made 10 years previously.

15. I do not know exactly what prompted the letter from the Scottish National Blood Transfusion Service to me in 2017. I have learned through reading on the internet that I was only now being contacted through a look back exercise that the Scottish Government had instructed.

16. I received an appointment at the new Queen Elizabeth Hospital in Govan, Glasgow. I saw a consultant around the 7th April 2017. I believe I saw

someone called Michael Johnston. The consultant told me that I was seen as a priority because of the letter I had received. The consultant carried out tests by taking blood from me. The test for Hepatitis C was carried out and I got the result back around 10 days after having the appointment. I got the result back which confirmed that I was positive for Hepatitis C. The consultant also advised me to get my three daughters tested as well and my ex-husband. I made those arrangements and they were all negative for Hepatitis C.

17. I asked for my medical records from my GP as a result of the letter and the meeting with the consultant. I have gone through them. My records show that the Scottish National Blood Transfusion Service didn't write to my GP about the infection when I was diagnosed 10 years previously. Having looked at my medical records I do not believe that the Scottish National Blood Transfusion Service ever tried to make contact with me. There is an entry in November 2007 which confirms that I am Hepatitis C PCR positive. I will share these with my solicitor.

18. I have only ever been given information about a website from the initial nurse that I spoke with when I got the letter telling me I was infected. The consultant gave me information as I asked him questions. He referred me to a liver nurse to talk to about my infection and she was really good. I think her name was Sister McTaggart. I also got really good help from a specialist nurse when I transferred from the Queen Elizabeth to the Gartnavel Hospital in Glasgow. The nurses have been the ones who have been the most understanding and supportive. All the nurses I have come across have been really good and the care I received from them was excellent. I was seen very quickly from being told I was infected. I got treated really quickly and I am clear 15 months later. I don't believe that most people have experienced this service from what I have read online. The one thing I would say is that when I received the letter I was left without any information or even any idea what was wrong with me. I find this very poor. No medical professionals or support contact has been

made with me and I was just left without any contact. I would say this is the poorest experience and I think the NHS could do better with this element of diagnosing individuals and support.

19. I do think that I was given enough information to allow me to manage the infection by the Hospital which was responsible for managing my infection. After I was told what infection I had, I also did some initial reading online which helped enlighten me and confirm what I had been told at the hospital.

20. I believe that I should have been provided with information at an earlier stage in the process of diagnosis. The letter that the NHS sent me should have given more information and detail. I should have been able to speak with someone when I received it regardless of it being a weekend. The letter should have said what the infection was because that caused a lot of stress sitting all weekend waiting to speak with someone. The NHS should have sent me a letter asking me to speak to my GP or someone professional to break the news that I was infected. I have since spoken to my GP about no one contacting me and having no support. I didn't receive much of a response from my GP. My GP practice GRO-B GRO-B

21. It was 2007 that the NHS said they originally found out that I had Hepatitis C. I had given blood and they tested it for antibodies as standard. The NHS knew I had Hepatitis C and no one ever told me until 2017. I want to know what happened. I want to know why they left it so long.

22. I remember the doctor at the hospital and Dr GRO-B was very informative about the risk of spreading the infection and being infected. Some of the information scared me to death as I was told not to share toothbrushes for example. I was worried by this as I had young children

who often use mine or each other's toothbrushes. They are older now but before I got them tested I was terrified. I was also told there was a chance my children could be infected when they are born and they had a 10% chance for each of them not to be positive. It a miracle and my ex-husband is fine which I'm delighted about. My ex had to have his new partner tested and his new family tested as well. It spreads out everywhere and luckily everyone is fine apart from me.

Section 3. Other Infections

23. I have not been diagnosed with any other infection other than Hepatitis C. I am unaware of whether I have been exposed to other viruses.

Section 4. Consent

24. I think that my blood was tested without my knowledge or consent. I know that when a person is giving blood it is always going to get tested and screened. I did not know that it was being checked for hepatitis C specifically.

25. Other than as I have described above, the information I was given was adequate when I was diagnosed. The letter I received telling me I was infected was inadequate, lacked information and failed to tell me anything. It was a source of distress.

26. I do not believe I have been tested for the purposes of research.

Section 5. Impact

27. The mental and physical effects of being infected were difficult. I think I have had this since I was around 18 years' old which is a very long time so it' s hard to differentiate between the time I was infected from when I didn't have it. If I was 18 when I was infected, I am 53 now so I have had it for all my adult life. Now I can see that I was always very tired and low. It is hard to differentiate as I have had 3 children, lost a baby who was stillborn and had a lot going on that might make me tired and low. I might have been more likely to have these problems because of my underlying infection, which I did not know about at the time. Now I am 53 I have a full time job as a field sales adviser, which is a full on job as I work 6 days a week. I am never tired and I never go for lie downs which I used to do. Even though my age is older and my job is high pressure I seem to cope much better than I used to manage.

28. No further infections or complications have resulted from infection.

29. I received various treatments for Hepatitis C. Initially because my liver wasn't badly damaged, the consultant Dr Johnston gave me new drugs. I was told by him that they tended to give the newer drugs to the people who are more severely infected. I don't know the names of the drugs I received. It is all in my records. I remember we started out with a mixture of Ribavirin and something else *(perhaps Interferon?).* It was a more traditional method which included injections for a month and after a month they measured the Hepatitis C count in my blood. I remember my blood count for Hepatitis C had not gone down very much, so they switched me onto the newer drugs for 2 or 3 months. The drugs actually did work in the end. It cleared the hepatitis. I have been for the post medical treatment now and I'm officially cleared of having Hepatitis C. I had a mixture of the old drugs and the new drugs so I am fortunate. I cannot remember the date I was told I was clear or the drugs which I was placed on by the Hospital.

30. I have not faced obstacles accessing treatment. Initially I was seen at the Queen Elizabeth University Hospital in Govan but after that I asked to be transferred to the Gartnavel Hospital, Glasgow which is GRO-B up from my house. This is more convenient for me. I transferred there and originally they were not sure when I could get treated but when I made the move to Gartnavel Hospital I saw the specialist nurse there. She was really nice and she gave me a date to start treatment. This put my mind at rest and she also said I could wait a year before starting treatment because my liver was not damaged. I wanted to start treatment as soon as possible and luckily while the drugs still affected me, I was still able to work through most of the treatment. It was the right thing to do for me. I just wanted to be clear of it and didn't want it for a minute longer. Some people have really bad side effects but I managed to get through it and I am glad I did because I could still be sitting here waiting for the new drugs. I have not faced any obstacles or difficulties in accessing treatment for Hepatitis C. I totally agree with what they did for me at the Hospitals. I couldn't fault my treatment there.

31. I don't know of any treatments which were available but not offered to me.

32. The mental and physical effects of treatment were gruelling but I just got on with it. I made myself keep going and working from home made that easier for me. I am the sort of person that just gets on and pushes through. I did struggle at times and the worry was very real as my children are very young. I just tried to push through tiredness and feeling sick as that was the way that I dealt with being treated. I think the actual treatment itself had a few side effects, but I followed the nurse's directions. I took them at the same time every day and I made sure I ate something with the medication. It is an individual thing that they can affect some people quite severely, particularly the older type of drugs. When I took the drugs there were not too many side effects and they did the right thing to clear me. Gartnavel Hospital did a Fibroscan to see how badly damaged my liver

was and luckily my liver was not damaged at all. I think I am very lucky that my liver has not been significantly damaged.

33. The infection has not impacted upon any other treatment for me including dental treatment. That is because I didn't go to the dentist until I was better because I didn't want to have to tell him. I am sure the dentist would have been very professional about it but I couldn't tell anyone. The thing that worries me is that I remember that I have given blood in the time after I got the Anti-D immunoglobulin and before they started to test it. I just wonder if anyone has gone back into my records to look to see about this impacting anyone else. I worry about this sometimes. I gave blood a couple of times but I cannot remember exactly when and where.

34. The impact of being infected is a difficult one to summarise. I never knew I had the condition for all these years. I haven't told many people even now. I have kept it to myself. My eldest daughter now knows but at the time it is quite hard as you don't know how severely you have been infected. When I was waiting for a fibro scan I was worried about my family. I didn't know if everyone was ok. I felt very anxious through that period of initial diagnosis and also very angry that nobody had told me. They had let me raise my 3 daughters and I was a Hepatitis C mother. I started to question if I was a good mother and whether my abilities as a mother has in fact been impacted on by having this disease. I have not been 100% fit my whole life and this must have impacted on my children. It will have affected how I was feeling.

35. There has been no stigma applied to my family. I have not told anybody unless they really need to know. I changed my job and started to work from home. I was working in field sales, which was physically demanding so I changed to do a job at home which was lucky because I would have struggled to work otherwise. This meant my work didn't need to know. I

was low risk because I was working at home so it was manageable as not many people knew. I followed the guidelines of things like not sharing toothbrushes. I told my sister but it's not the sort of thing that I wanted to share.

36. Due to my diagnosis I took a different job doing telephone sales on the phone from home. I was in the house all the time because if I was feeling rough it was still fine to be on the phone. This means that I didn't have to worry about my appearance. If I had to continue with field sales which was my original job at the time, then it would have been very difficult. I have a family to support so I don't have the option. I was fortunate that I had a job that I could switch to to keep money coming in to the house.

37. I was looking for other work when I got that letter advising of the infection. However, I chose a job that meant I could work at home. It allowed for me to get treatment but at the time I was looking for something else. The infection affected what I chose to do for a job. Field sales was very high energy but in telesales you don't have the physical interaction with people so you don't have that pressure. It was a conscious decision. I have gone back to what I used to do now in field sales because I feel better now.

38. The financial effects of being infected were difficult. When I applied for the infected blood scheme last year I did it because I knew that I was going to have treatment. I thought it would help me support my family. If I had received any sort of financial assistance, I would not have had to work. Due to having no financial support I had to work. This is annoying because I feel I was entitled to this and it would have made my life a lot easier as I wouldn't have had to work for 2 or 3 months while I was going through treatment. I have two children that are dependants at the moment so there is constantly financial pressure alongside parenting. I was not really affected by any other financial products as my employer at the time didn't have any life or health insurance with them. The only thing I had to do was

when I went to California last year, I took travel insurance, and the premiums were slightly more but not massively expensive.

39. The effect on my family and friends was marked. I told my ex-husband I was infected after all the girls were tested and I knew they were all ok. I did this as I did not want him to have the 6-8 weeks being worried about it. He was quite annoyed with me for not telling him. The girls were quite worried about the testing and waiting for results. No one could give me reassurance that they would be ok and not infected. I asked the GP to not tell them what they were being tested for as I didn't want to worry them too much. I just told them they had to give bloods to be tested for something that mum had. I didn't go into detail because they worry for you and themselves.

Section 6. Treatment/Care/Support

40. I have not encountered any difficulties or obstacles with treatment. I think that is because of the circumstances in which I was diagnosed. I just wanted rid of it as soon as possible. The nurses are lovely. I was offered a mix or the older/newer drugs. I was given the option of starting treatment immediately or of waiting for a year or more to have the newer drugs with less side effects. I chose to start immediately.

41. No psychological counselling has ever been suggested to me but I suppose if I had asked or if I had appeared depressed I might have been referred but I don't know this for sure. I tend to act like someone who can cope as I tend to deal with things internally.

Section 7. Financial assistance

42. I found out that financial assistance was possible from searching online. I understood that there were trust funds for people who had been infected like me. There was the Scottish Infected Blood Scheme and I thought I would be able to get support. I looked into the fund and found out that it didn't cover someone like me who had received Anti-D immunoglobulin because they consider that it would have been be safe. I phoned up the Scottish Infected Blood Scheme and made a general enquiry as to whether people like me are excluded. I thought they were going to come back to me and say I was excluded however the Scottish Infected Blood Scheme didn't react like that. They read out a statement from a Scottish Blood Policy expert or something like that and it raised my doubts about what I was possibly entitled to in terms of financial support. I therefore tried to apply to the fund.

43. I had to give the application to my consultant Helen Cairns to confirm my diagnosis and to confirm that I had received Hepatitis C. I understand that she was going to pass it on. I have not yet received the application completed. I never heard anything back from him or the scheme. I don't know if the form got sent on by her to the scheme or if the hospital still has it right now. I have been unable to find out the position. I have not received any payments.

44. I don't know about preconditions to the application. When I phoned the Scottish Infected Blood Scheme they initially said I was not eligible but then the position changed as I have said above.

45. The only obstacle I have had to applying for financial help is that my application has been paused and nothing has happened which I think this is strange.

Section 8. Other Issues

46. I have two documents which are relevant to this statement but both of these documents are in my medical records. There is a letter saying that I was tested 10 years ago. I think this document proves I received Anti-D immunoglobulin. I ask Thompsons Solicitors to recover my medical records on my behalf and I be given the opportunity to review these with Thompsons in full together. It may be that I will wish to give a further statement to the Inquiry once my full records have been made available to me.

Statement of Truth

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

Signed: GRO-B

Dated: 28/2/2019.