Witness Name: GRO-B
Statement No.: WITN0149001
Exhibits: WTN0149002-006
Dated: 8th March 2019

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 5 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 1958 and my address is known to the Inquiry. I am married to GRO-B. I intend to speak about my experience of becoming 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 family and our lives together.

Section 2. How Infected

2. I contracted Hepatitis C on GRO-B 1977, when I received a blood transfusion due to complications in the birth of my first daughter, GRO-B.

Following GRO-B birth, I received 2 pints of blood. I have identified an entry in my medical records describing the blood transfusion during GRO-B birth dated the GRO-B 1977 which I exhibit under **WITN0149002**. I gave birth at the Simpsons Memorial Hospital, Maternity Pavilion. I had my three daughters there. When I gave birth to GRO-B, I lost a lot of blood and had a haematoma, which is the reason why I required the transfusion. I cannot remember the names of any of the doctors treating me as I every time I went to the doctor for maternity related matters, there was a different doctor treating me. The blood transfusion I had on GRO-B 1977 was the only blood transfusion I have had. Although I had a miscarriage after the birth of GRO-B and also experienced complications during the birth of my second and third daughters, no further blood transfusions were required on those occasions.

3. I found out that I was infected with hepatitis C about two years ago in 2016. I have found a note of the consultation in my medical records dated the 5th July 2016 which I exhibit under **WITN0149003**. This was when my GRO-B daughter GRO-B: D was pregnant with her second child. D had a blood transfusion in 1981, when she was born premature. Throughout her second pregnancy, D was itching constantly. She just could not deal with the itchiness, it was really bad. D itching throughout her pregnancy led to further investigations and ultimately tests that diagnosed her with hepatitis C. D found out that she had contracted Hepatitis C from the blood transfusion she received in 1981. That is when we all decided to get tested. From these tests, I found out that I also had hepatitis C, which I had contracted in 1977 at the time of my blood transfusion. I have identified a referral letter from my medical records dated the 1st August 2016 which I exhibit under **WITN0149004**. In this letter, Sara Lamond acknowledges I could have had hepatitis C for 30 years without knowing and how worried that made me.

4. The reason why D required a blood transfusion at birth is that she was born premature and she experienced complications and respiratory problems. She was born on GRO-B 1981 and when I went to see her, she was in the incubator; there was blood on her covers. When I saw the blood I was horrified but the nurse told me that D had been given a blood transfusion.

No one asked me beforehand before proceeding with the transfusion. I was also there in hospital and it would not have been any hassle to ask. However, I wasn't asked and was only informed once the transfusion had taken place. It is important to save someone's life but there could be religious reasons why some people might not want a transfusion. I believe that the right procedure to follow is to ask before administering a blood transfusion. If I hadn't seen the blood on D covers, I would never have known that she had a blood transfusion.

5. D and I have had tests over the years where our liver enzymes have been checked as a matter of procedure, however until 2016, we were never tested for hepatitis C.

6. We were never told about the risk of infection beforehand and we were never asked whether or not we wished to proceed with a blood transfusion. I was just told that I needed to have a blood transfusion and I know that I would have died without it. I was 18 years old at the time and I was not aware of any consequences and was not told that there would be any.

7. I found out that I was infected with hepatitis C because we all went to the doctor and got tested after D hepatitis C diagnosis. Our other two daughters were fine. The next day, I received a call from the receptionist who asked me to come in the next day. I was worried due to the urgency of the appointment. Dr GRO-B, now retired, told me that I had tested positive for hepatitis C. She said I could either go to the Edinburgh Royal infirmary or go to the Western General Hospital for treatment. I asked why I had hepatitis C and the doctor said that chances were that I had contracted it from my blood transfusion. However, the doctor said she didn't know anything about medication for hepatitis C. I am well aware that I couldn't have gone to my GP for anything to do with hepatitis C, as GPs did not have any knowledge about hepatitis C and they openly said this. I got sleeping pills from the hospital because my sleep patterns were even worse after I started the treatment for hepatitis C.

8. I attended the Western General Hospital and my nurse, Sarah, was lovely. I could telephone her any time if I needed anything. The medical staff were not overly informative. They said that the tablets prescribed would take my hepatitis C away. I got the impression that even Sarah was not 100% certain about all the information. My daughter chose to go to the Edinburgh Royal infirmary instead and she was told to wait for treatment as she was pregnant and then breastfeeding.

9. I cannot remember the name of the doctor who treated me at the Western General Hospital. He did sign my forms when the time came to apply for financial assistance. I only saw him twice and that was when I required his signature when applying for financial assistance and when filling in the forms for the same purpose. My contacts at the Western General Hospital were Sarah and another nurse who took my blood. I was treated at the infectious Disease Department, which was embarrassing for me.

10. In order to understand and manage the infection, I was told what medication to take. I had to take eight tablets a day including Ribavirin. I have identified an entry in my medical records describing my medications for the treatment dated the 3rd of October 2016 which I exhibit under **WITN0149005**. I was given a dosage box to put my tablets in and was warned about sleep disturbances. At some point, my white cell count was low and I had to get that sorted as well. I was off work for five months. I am a carer and could not remember anything within a 5 minute timespan because the treatment really affected my memory.

11. No advice was given regarding lifestyle choices. I was told to abstain from alcohol as my liver was inflamed. I used to socialise and have a drink now and again and now I cannot drink anymore after the treatment. However, when I was told to abstain from alcohol it felt like, for the medical staff, this was an afterthought rather than priority advice. My liver is now the same as everyone else's or so I have been told by my nurse. I think that the treatment has

changed me and changed my marriage. I do not really know why but I feel that it has.

12. I think that information about hepatitis C should have been provided to me earlier. The reason why I say this is because I went to the Opticians during a time where I had to attend different Opticians than I normally did. It was there that I was told that I presented some changes and that it looked like my cholesterol levels were quite high. I was surprised because I used to go to the gym and I didn't eat any unhealthy food. This conversation with the optician made me go to the doctor and get tested. I was told by the doctor that my cholesterol levels were fine but my liver enzymes were quite high. I got checked again sometime after that and my liver enzymes were high. The doctors asked how much I drank but I said I was not a big drinker and that was the end of the issue. No one even thought that I should be tested for hepatitis C and no one chose to look into it. I have identified an entry in medical records dated the 10th of July 2014 which I exhibit under **WITN0149006**. This shows biochemistry results from one of those tests where my ALT levels were shown to be 138 U/L. Despite this result, no one chose to investigate it or the possibility of me having hepatitis C and I wasn't made aware of my hepatitis for a further 2 years. The truth is, if it was not for my grandson being born, I wouldn't have known that I was infected with hepatitis C at all.

13. When my daughter was pregnant she was at the GP every day complaining about itches up until the point when the hepatitis C was discovered. After her hepatitis C diagnosis, my daughter was given her own cotton bud to dab herself as the nurse would not even touch her. The nurse even went as far as to imply that my daughter needed to speak to her husband regarding the hepatitis C. As if to say her husband had been having an affair and that is how she had contracted hepatitis C. The medical staff later realised that the hepatitis C had actually come from a blood transfusion. I think that they should have been more diligent and they should have looked into it earlier than they did. For years I used to have this feeling of pressure on my liver, which was

dismissed by the doctors as floating ribs. I now think this was related to the hepatitis C affecting my liver.

14. My opinion on how test results and information about the infection were communicated to me was that the doctors seemed as shocked as I was that I had hepatitis C. I only took the test because my daughter had it, the doctor was not really understanding towards this issue. I think she was quite ignorant about the condition. Also, the doctor just blurted out that I had it and I feel that she could have sat me down and explained it better. She could have taken a different approach.

15. Regarding the risks of others becoming infected as a result of my hepatitis C, the doctor said we should all get checked. I was also told it is very rarely sexually transmitted, so my husband would not be at high risk. In my opinion, the GPs don't know enough about hepatitis C. I later found that my daughter was on just one tablet a day when she had her treatment rather than on eight tablets. This was simply because the medication had changed by that point due to my daughter having to wait until her son was born, she had just finished breastfeeding at the time. When I went to hospital for an appointment regarding my hepatitis C, it was not very different from the appointment I had at the GP. I was just told hepatitis C was a blood borne disease, I don’t think I was even told to be careful with cuts, for example, that could happen in the kitchen. I really cannot remember but I don't think that hygiene of cuts and wounds was discussed with me.

Section 3. Other Infections

16. I do not believe that I have ever received any infections other than hepatitis C as a result of my blood transfusion. I have certainly never been warned about the risk of CJD.

Section 4. Consent

17. I do not believe that I have ever been treated or tested without my knowledge, without my consent or without being given adequate or full information. The only thing I would say is that when I received a blood transfusion at the time of my daughter's birth, I was not asked or informed of anything.

18. I do not think that I have ever been treated or tested for the purposes of research.

Section 5. Impact

19. When I found out that I had hepatitis C, I was really upset about it. I think that it has changed me as a person. It has changed my marriage and my socialising habits because I don't feel like socialising as much due to the fact that I cannot think. It has made me really depressed in the past and I still struggle with it, although it doesn't really show as much. I was disgusted that something like hepatitis C had been in my body. Physically I felt really tired, I just needed to sleep. On a different note, my fingers go white when temperatures are cold. This means that I developed Raynaud's disease. I have had mild asthma since my early 20s and do not know if it is related to the hepatitis C. I also developed a really dodgy stomach, due to the illness. This means that I require to go to the toilet more often because I suffer from irritable bowel syndrome due to the medication. This causes me to panic when I go on holiday, particularly if we have an early flight. I even worried about you coming here to take this statement. I also worry because when working as a carer I don't always have access to toilets when I am out and about with patients. I never used to be like that. Mentally, I felt really dirty because I think hepatitis C is a dirty disease and I am ashamed that I had it. I had to tell my work about this as I required to be off when I was on medication and it was extremely embarrassing. I still do not want anyone to find out.

20. I do not have cirrhosis of the liver, although for some time my liver was inflamed. My liver is back to normal now. I do have irritable bowel syndrome. I have depression but I am not on medication for this. I am still tired through the day and I cannot sleep at night so I take sleeping pills. I am now working part time and this allows me to come home for a nap as I require to sleep through the day due to the fact that it is extremely hard for me to get to sleep at night. I was given the sleeping pills while I was taking the medication for the hepatitis C and I take them every night. I think what is keeping me awake at night are my thoughts about the infection. I do not want to be taking the sleeping pills forever. I think a lot about what happened and even more about what could have happened if the hepatitis C had remained undetected or had been worse than it actually was. I am still worried that it is going to come back in a few years and things just escalate in my mind at night.

21. My treatment for the hepatitis C was 8 pills a day for 12 weeks including the Ribavirin. The treatment was successful. I had the treatment as soon as I found out that I had hepatitis C, so there were no obstacles for me.

22. I do not think that there were any treatments that should have been made available to me that weren't. I just wish I had found out about the hepatitis C earlier. However, I am also aware that if I had waited a few months like my daughter, I could have taken only one pill as she did. The treatment I had was eventually discontinued. As a result of my treatment, I have arthritis in my toes, Raynaud's disease, and irritable bowel syndrome that have been caused by the medication I was taking. I also have aches and pains in my fingers. At the same time, I do not know if I could mentally have waited for a few more months to have the new treatment for hepatitis C.

23. The mental and physical effects of the treatment were horrible. I had terrible memory problems, was always weepy, short tempered, depressed and at times too outspoken. I really felt like one of my patients with dementia that I care for. I could relate to them. I was totally miserable and drained. I am normally laid-back and not outspoken but the treatment could make me

excessively outspoken at times. Physically, I was tired but my teeth and hair did not fall out as a result of the treatment. I did feel nauseous, but was not actually sick.

24. The treatment had an impact on my family life. I was really depressed. Normally I love having Sunday dinner with my family and going out shopping with my daughters. I am not the same anymore. For a while I stopped organising Sunday dinner get-togethers with my family. I have recently gone back to reintroducing this. At times I could be short tempered and I hated noise. During the treatment, I didn't have patience with my grandchildren. I also feel like my husband had to bear the brunt of it as well.

25. I feel like there is a stigma about having hepatitis C. I feel like this is something that I don't ever want my neighbours or anyone else to know about. While I was attending the Western General Hospital, I was terrified I would bump into someone that I knew there. My husband, my daughters, my sister and my best friend know. No one else knows that I was infected with hepatitis C. Even my own brothers don't know because it is embarrassing. Hepatitis C is the same disease that drug addicts have.

26. Becoming infected with hepatitis C did not have any effect on my education. However, I feel that becoming infected with hepatitis C did have an impact on my career. After the treatment, I had to go back to work part-time. I don't feel the same at work anymore. I am still good with GRO-B but I get very tired. Prior to treatment, I used to work between 8AM and 1PM and then again between 4:30PM and 10PM, four days on and four days off. When I had my treatment, I had to be off work for five months. Now I am working from 8AM to 2PM only and do not go back to work at night. This is because I need more time to sleep as a result of my tiredness

27. Finances-wise, my wages have been reduced as I am now working part time; this has meant that a big chunk of my wages has been taken away but I could

not work full-time anymore. This means that I have had to tighten my belt a bit more.

28. Being infected with hepatitis C did not really have an impact on my medical treatment. This is because I never told my dentist that I was infected. The nurse at the Western General Hospital said that I did not have to tell anyone about my hepatitis C if I didn't want to do that because the medical staff should have the proper precautions in place anyway. My medical treatments were not affected. My treatment for asthma, which is an inhaler, was not affected. I could still use this.

29. Becoming infected with hepatitis C did cause me to stop going to the gym because I was breathless at times due to my medication. I realised it was actually making me feel worse. I have only recently started going back.

Section 6. Treatment/Care/Support

30. I was not offered any counselling or psychological care or support due to becoming infected with hepatitis C. I think it would have been a good thing for me to have the opportunity to sit one-to-one with a counsellor.

Section 7. Financial Assistance

31. I did receive financial assistance as a result of becoming infected with hepatitis C.

32. I received £20,000 and then £30,000 when I found out and my wages were made up when I went off work. I am now receiving around £1,561 a month. That helps a little bit as I am now working part-time.

33. I think that the first £20,000 payment was received from the Skipton fund and thereafter further amounts that I have been receiving are coming from NSS.

34. A nurse told me about the financial assistance. I also received letters from Skipton and from NSS telling me that I was entitled to financial assistance. The process of applying for financial assistance was quite straightforward. I had to fill in a form and no access to my medical records was required but the doctor had to sign the forms the first time.

35. There were no obstacles for me in applying for financial assistance, I just felt embarrassed, as if I was begging for money. My family have always worked hard for our money and never had anything given to us.

36. I do not think that there were any preconditions imposed on the making of an application for the grant of financial assistance.

37. The financial assistance received has helped me out. The money that I have received is not a lot but it does help. It is generous but it is probably something that I deserve. I would probably be better off working full-time but I cannot do this anymore after my treatment. I still feel like I have to tighten my belt with all the bills and mortgage. My husband is working but he is older than me and I feel like it is getting too much for him at times and he just has to keep doing it.

Section 8. Other Issues

38. I have not been involved in the Penrose inquiry. I have not been involved in any court proceedings or in any campaigning as a result of contracting hepatitis C.

39. My husband like to keep up-to-date with the Forum online but I don't even want to look at it. I have thought about going to the Infected Blood Inquiry Hearings coming up in Edinburgh and I have spoken about this with my husband but we are still to make a decision.

40. I do not think that any parts of my medical records are missing. In particular, the part about my blood transfusion is very accurate. I had a fever after the transfusion; I think this was the hepatitis C kicking in. I had a miscarriage a few years later and I do not know if this was related to contracting hepatitis C, I will probably never know.

41. I think the hepatitis C should have been picked up by the doctors a long time ago. I should have been tested. I felt like a guinea pig because I was never even asked if I wanted the blood transfusion. I went on to have a miscarriage and another two children and it was never detected. I feel like someone might have known that I had hepatitis C. My daughter D was given a blood transfusion when she was born without me being asked. I had haemorrhages with my other two daughters but these were contained.

42. I would like my statement to be made anonymous. My daughter D is very frightened that people will find out about her infection. Only her sisters, her dad, her husband and myself know that she contracted the infection and she would be very angry if anyone else found out. GRO-B
GRO-B
GRO-B

Statement of Truth

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

Signed GRO-B ________________

Dated May 1, 2020