Witness Name: GRO-B
Statement No.: WITN2246001
Exhibits: None
Dated: 18th February 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 5th November 2018.

I, GRO-B will say as follows:

Section 1. Introduction

1. My name is GRO-B. My date of birth is the GRO-B GRO-B 1935. My address is known to the Inquiry. I am living at home alone and I am retired. GRO-B GRO-B. I intend to speak about my about my infection of 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, my family's life and our lives together. I wish to be anonymous for this statement

Section 2. How Affected

2. In the summer of 1973, my ex-husband left me [redacted] [redacted]. I was sterilised later in the year on the 5th December 1973. On Christmas morning 1973, I collapsed in a severe amount of pain and an ambulance was summoned. I was admitted to the Royal infirmary Edinburgh and ended up having an operation on Boxing Day early in the morning. There were lots of investigations and I can recall that a doctor came to see me and said *"We are going to save you, but you have to tell us. is there anybody here to sign this form as you only have about 15 minutes to live. We have to operate."* Someone then went on to sign this form but I do not know who it was. Perhaps it was the police but I do not know now. I then went on to have a laparotomy. I had an abscess in my ovary in one of my tubes and it was life threatening, I was full of poison. After about 3 to 4 weeks in mid-January 1974, I asked to go home from the hospital, I felt better and needed to get back home to care for my children and was discharged from the hospital on the 8th January 1974. On discharge, I was given medicine to take because I was anaemic. On the 19th January 1974, I felt very sick and started to throw up green sick and was readmitted to the Royal Infirmary Hospital, Edinburgh and I had to have another laparotomy. I am covered in scars from this on my stomach. When the hospital did the further laparotomy, it was discovered that I had a blocked intestine. I am not sure if I received another blood transfusion for the second operation. When I was discharged on the 1st February 1974 I was told I would have to go back to hospital for a check-up. When I attended my check-up appointment the doctor said he was happy to see me and didn't know how I was still alive. The doctor also confirmed to me that I had received a blood transfusion.

3. Everything was fine, I got on with my life and my health was fine. I worked all the time, so much so that my eldest daughter ended up providing a lot of support to me with raising the other children. In January 2009, I took ill; I was not able to do any daily tasks. We went to the doctor and they did tests that showed that my results for my liver were elevated which was a big shock to my family and I. I was then referred to the Western General Hospital,

Edinburgh for further tests and after testing I met with Professor Leen who told me I had hepatitis C. He reassured me that I was still healthy but I had options around treatment. Professor Leen recommended that I start treatment straight away and in June 2009, I started interferon treatment which involved injections into my stomach.

4. They gave me a leaflet at the Western General. My GP said he was going to refer me and I remember him saying, *"Can I ask you* GRO-A *are you a drinker?"* I said, *"No"* and I was referred. At the Western General, Professor Leen explained to me that I had hepatitis C. I said, *"What is this?"* and he asked me if I had ever had a blood transfusion in the past. I said yes and he explained the condition was something that I would probably not see any more effects for, for probably another five or six years but he recommended that I start treatment straightaway. In June 2009, I started interferon which involved injections.

5. No one knew I had hepatitis C until 2009 so I was told by the hospital when they found out. To find out full information though, my daughters had to look up what hepatitis was on the internet.

6. When I was diagnosed, things were explained quite well to me around the basics. The conversation was mainly focused on treatment though.

7. There was never any conversation about the risks associated with having a blood transfusion or the risks of spreading the infection. I just remember the form that was waved me. In the leaflet when I was diagnosed, it told me that the infection could be spread if I cut myself on a razor, it was quite rare but possible to spread the infection through sex. My family had to be tested as well, GRO-B

Section 3. Other Infections

8. No, I am not aware of any other infections from the blood but I wonder what else is in the blood that we don't yet know.

Section 4. Consent

9. Yes, they did not tell me when they were testing me for hepatitis C. They said I was going to be tested for a variety of things. My GP did not tell me that I had the infection; he just asked me if I was a drinker and referred me to the hospital to explain. All they would say is something is not right with the liver, that it was elevated. It was when I was referred and in-depth investigations were done, that Professor Leen confirmed my diagnosis.

10. In 1973 I could not give consent, I do not know who signed that form, whose signature that was, so I didn't consent to receive blood. On the other hand, the doctors told me I had 15 minutes to live.

11. I was not given full information about what could have happened with the interferon. That started off well, but no one was expecting that reaction. It was a lack of care. I was complaining about how I was feeling but no one was paying attention, no one said, "*Okay, this drug is not agreeing with you, let's stop*", they kept me on it until the very end. I was dying. I wanted to see Professor Leen, but I was just left to cope until it was too much. It was a lack of care. I discuss what happened in section 5.

12. Maybe, I do not know. They did not know how to manage my condition. It was like there was difficulty getting me well again; they were having to seek support from consultants outside of the Western General. I felt like a guinea pig. It is a strong potent medicine, they must have experience with the medication. I am not a young person now; I was 75 when I started this. It was not appropriate that I was put forward for the treatment at all. The nerve damage to my legs will never go away due to the interferon treatment.

Section 5. Impact

13. I felt weak, I felt like something was in my skin. I could not do housework. I was not strong anymore. I was upset because I have never been ill in my whole life. I thought *"My God I'm getting old"*, emotionally I was also very upset and I was confused, nothing makes sense for the hepatitis.

14. I have now developed liver cancer which was diagnosed on the 17th October 2018. Dr Bathgate has supported me with this. There is a tumour on my liver. Dr Bathgate recommended a procedure called Transarterial chemoembolization (TACE) procedure and I had this procedure in November 2018. After discharge, I was very weak and was poorly for approximately 3 weeks spending most of my time in my bed. Dr Bathgate explained he would arrange a further MRI scan in the near future to see if treatment had been successful. I am treated at the Royal Infirmary Edinburgh. When I was diagnosed, I was very distressed and felt anger towards my ex-husband for having him in my life, GRO-B, become sterilized, having operations in 1973 and 1974 which led me to have a blood transfusion, which has led to chaos and my world being turned upside down.

15. One of the main issues of why they could not get on top of the interferon disaster for me was that the interferon caused my liver to be decompensated, i.e, an advanced form of cirrhosis. In addition, the treatment caused nerve damage to both my legs and I had a fever or infection that they could not establish the reason for this. My liver was not functioning basically, I have never been ill before then, but since then I have never recovered properly. The treatment did not destroy the virus but it did destroy my life. When the new treatment came along, I was given this in 2015 and now I no longer have hepatitis. When I was on this treatment, GRO-B and as my daughter was worried about the heat, we went to the beach later in the afternoon and I collapsed. GRO-B screaming for help, she believed I had died; it was awful. An ambulance came but I refused to go to hospital as I felt ok, I think I was just dehydrated. The ambulance paramedics put it down to

being dehydrated as well; because I refused to go to hospital I do not know if this was in any relation to treatment. I was clear of hepatitis in 2016. The treatment was comprised of harvoni and ribavirin. The hepatitis is gone, however due to cirrhosis I now have liver cancer. I have had to go back into hospital numerous times since 2016, as there have been complications with varices. I was given a choice to have medication to reduce the chance of clots from this and my other choice was to have procedures done for which I said yes to. I have had numerous procedures with the objective being to strangle the varices. This tumour has come about because I had hepatitis, which developed into cirrhosis, which has now turned into cancer. In August 2018, I had my routine six monthly ultrasound and soon after received a letter to have an M.R.I scan and after this I got a letter from Dr Bathgate and a formal letter from the Royal infirmary Edinburgh inviting me to come and discuss the results. Even the tone of the letter left me worried; it was obvious there was something seriously wrong. I went to hospital with my daughter GRO-B and we received the results in October 2018; we were stunned. I was told that the tumour was about 2 1/2 cm long, however I could not take any information at that point, I was just too distressed, as was GRO-B.

16. I was offered treatment of interferon which I started in June 2009 and was under the care of Dr GRO-D who was supposed to be monitoring my interferon treatment. I was okay but from November 2009 to January 2010 things started to decline and I had a big reaction and was experiencing adverse effects, as well as falls. I previously complained to Dr GRO-D about the shooting pains in my legs and despite this the interferon treatment continued. In late January 2010 I was gravely unwell and my daughter GRO-B spoke with Dr GRO-D on the phone and she said if Dr GRO-D did not arrange an ambulance to take me to hospital she would call the emergency services. I was then admitted to the Western General Hospital (Infectious Diseases Unit) and they started running nerve conductor tests and found that I had nerve damage and it was most likely linked to the interferon treatment. The interferon stopped after a few more days and then I just began to swell all over my body. I was in hospital after this from January 2010 to June 2010 and I was under the care of Dr GRO-D After about a week in hospital, I fell and

broke my tooth. I could not walk to the toilet and I needed a full hoist, I had to be catheterised, and then my body just totally blew up. They could not give me medication because I was having problems with my potassium/sodium levels as well. The hospital was struggling to figure out what had happened to me, as it was so rare. After this I needed morphine to help manage my pain and was barely able to function. Before I could be released from hospital I had to learn how to walk again, I was that weak. I was drip fed for months because I had problems with my albumin, I was having regular scans and x-rays. The doctors did not know if I was going to make it, eventually we got through it but before I was released I had to get a physiotherapist involved, doctors and dieticians, it was a long and difficult process. In April, I started to pick up; I was on steroids as well. I am very, very angry at the doctors for what they have done to me, I remember screaming at Dr GRO-D when I was in hospital, I saw her walking down the ward and I said to her *"What have you done to me, you've ruined my life!"*, she put her head down and walked away. I saved my own life through my strength. No one could speak to me, I previously told Dr GRO-D of the shooting pains in my legs and of the falls at home but she did not listen and the reaction of interferon caused my liver to be decompensated, which was why my system was unable to cope with interferon treatment. Dr GRO-D did not listen to me, I felt she did not care. When I came out of hospital, I was skeletal, it was two extremes, I blew up like Pavarotti in hospital but I was a skeleton when I was released in June. I went through hell there; I was not supported by the Western General properly then. Professor Leen did not come to see me, Dr GRO-D did not come to see me, I saw only Dr GRO-D and Dr GRO-D when I was hospitalized.

17. There has been no impact on any other medical treatment for me in relation to the hepatitis C, the medical professionals are all aware of it. A few years ago, I had to pay for specialist treatment, I had implants done on my teeth, everything was sinking into my gums and I had to tell one specialist dentist I had hepatitis C which was very embarrassing.

18. I stopped working when I was 60 or 65. I was working as a home help, I worked in a bakery in the afternoon, I had lots of odd jobs. There was no impact on my working career.

19. I have had no financial issues in relation to the hepatitis. I cannot remember if there was an impact on insurance when I went on holiday [redacted] but I can recall that [redacted] bought travel insurance for us and it was more expensive for me.

20. It is a grieving process; my family were grieving for me. It has been horrendous for them. Ever since I have been diagnosed, it has been a rollercoaster, it has affected everyone. [redacted] had to take two months off work to support me when I became incredibly unwell with the interferon in January 2010. I used to have 100 pairs of shoes, I love shoes but now I cannot walk in any of them, I can barely walk at all because of interferon. I have been under a horrible amount of stress as have my family. When [redacted] went off for two months with stress, she felt like she was going into cuckoo land, every time she walked into the hospital, there was always something new going on. I was not really aware of what was going on during this period, I was too out of it on morphine, [redacted] says that she had no strength to speak with me. If I had been aware, it might have distressed me as she was in tears all the time and a total wreck, she felt helpless. The doctors could not give her information and she did not know what to do to help me. Afterwards, it has been a constant worry for her, for the whole family. [redacted] always phones me from work to check on me, she is always waiting for the phone to ring in case something else has happened, it is stressful. In October 2018, the cancer diagnosis was a shock for the whole family when I was diagnosed. They knew cirrhosis could develop into liver cancer but never for one moment thought I would get liver cancer but then one tumour just suddenly happened. It has just been awful for everyone. [redacted] It is something that she thinks about in the morning and last thing she thinks about at night. I want my life back but it is never going to happen. There is no paperwork to prove that I have had a blood transfusion, it has been destroyed by the NHS. I have trouble walking and there are several

flights of stairs up to my flat, I can do it but extremely slowly. There are days I cannot get out of bed, I am not the same person and my family have had to support me with all of this. The hospital arranged for community physio when I was discharged from hospital for 6 weeks which was later extended. The physiotherapist and their team helped me with my walking and provided exercises to help strengthen my legs. I was offered a package of care for someone to come to my home to prepare my meals however there was no point as I don't eat microwave foods and I had my family to support me, to eat healthy foods. When I started to get better in hospital and was able to eat, my family had to bring in food from home in a flask, I have grown up in a different culture and I did not like most of the foods provided to me in the hospital.

Section 6. Treatment/Care/Support

21. Further to the above, no psychological support has been offered to me. GRO-B GP was very supportive to her when she was really distressed and not coping when I was in hospital. After GRO-B GRO-B as I describe above because GRO-B and GRO-B had to ensure that I was being supported and helped at home. GRO-B so she was a better position to work around her hours. The family have really supported me through this but they were also struggling to come to terms with it, there was no psychological support for them, which may have assisted them in coming to terms, it was a grieving process as I say.

22. I do not discuss the hepatitis with anyone, I am a private person, the family know but no one else treats me any differently. I do not want anyone to know.

Section 7. Financial Assistance

23. GRO-B found out about the existence of Skipton through her own research. There was a lot of media coverage, which brought it to her awareness. She knew it was not right that I had had this; she was looking to get compensation for me for the heartache, for the whole family. Thompsons Solicitors retrieved

paperwork that I was in hospital but there was no evidence about the existence of a blood transfusion. Therefore, I was awarded nothing. I now have a tumour because of this. It was an ultimate slap in the face. It was as if they were suggesting that I had contracted hepatitis C through other means, which was so frustrating as I have never been with anyone but my ex-husband. I am not lying about the blood transfusion; I was told by the doctor at the time that I had had this. My medical records have been destroyed now and it was Skipton who made this determination in 2010 or 2011. I appealed the Skipton Fund decision and Dr Joanna M Turner from the Western General Hospital, Edinburgh wrote a supporting letter to the Skipton Fund but they said no ultimately.

Section 8. Other Issues

24. It is unacceptable that I have received nothing…disgraceful. Because the NHS have destroyed my records which shows their negligence, I am now left with no compensation, which I am entitled to.

25. Thompson Solicitors will be recovering my medical records once again for which I will be given an opportunity to review.

Statement of Truth

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

Signed **GRO-B**

Dated 29. 3. 19.