Witness Name: GRO-B
Statement No: WITN1921001
Exhibits: WITN1921002
Dated: 27.11.2018

WITNESS STATEMENT OF GRO-B

INFECTED BLOOD INQUIRY

Section 1: Introduction

1. My name is GRO-B My date of birth and address are known to the Inquiry.

Section 2: How Infected

2. It happened on 23rd May 1986 at GRO-B I was pregnant with my first child, she was not due until June but I went into early labour and was admitted to hospital on the 19th of May.

3. On the 23rd of May I was told by the ward sister that I had to have a transfusion because of my blood results. She was incredibly harsh with me, she just said that I had to have it because the doctor had said so. I know now that I had anaemia and this is why they gave me a blood transfusion. I had a low red blood cell count before I was pregnant and have been anaemic ever since.

4. A nurse stuck a cannula in my hand, hooked me up to the blood and started the transfusion. Suddenly, before it was finished, a nurse came and took the tube out

of the cannula, gave me a cellular blanket and told me that I had to go for an ultrasound scan. The whole thing was quite strange. I wondered at the time why I had suddenly been sent for an ultrasound scan and whether I was meant to have the transfusion, or whether it was meant for someone else.

5. I was sent off the ward by myself with just a blanket over my hospital gown and with the cannula still in my hand. I had to walk outside across the hospital grounds, past a group of workmen to a separate block where they gave me an ultrasound.

6. When I arrived the radiographer was horrified that they had sent me by myself. I was having contractions while she was scanning me. She told me that my daughter was ok. Then she phoned the ward to make a complaint about the way I had been treated. She insisted that they send a porter to collect me and take me back to the ward.

7. When I got back to the ward I was told by the woman in the bed next to me that there had been a bit of a hoo-ha while I had been gone. She said that there had been raised voices between the staff on the ward, and that it sounded as if someone was having a go at someone else. I thought that it might be because of the complaint that the radiographer made but even at that time I did wonder about the blood. It seemed strange that I had been having a transfusion and then suddenly was given a blanket and sent off the ward and out of the building by myself.

8. I was never told anything about any risks of the transfusion. The ward sister was so sharp with me when she said that I had to have the transfusion, it was quite horrible. She used the same tone as she had used when she gave me an enema. There was never any information; her attitude was that I just had to have it done. I was a teenager and a young mother, I did not question her.

9. As a result of this transfusion I was infected with Hepatitis C.

10. In June 1987 I suddenly started not feeling myself. I felt low; they put it down as depression. I could not understand it because there was nothing wrong in my life and no reason for me to feel down. From then on life became a struggle mentally and physically. Since then I have not felt right, I have not felt well.

11. I worked for as long as I could. I worked for a large retailer as a part time shelf stacker, I was promoted several times and had just accepted a role as a trainee manager when I started collapsing at work from exhaustion. I had to give up work in 1998. I did not work again.

12. I felt that I was carrying 10 other people around with me. I could not understand it, I did not know that there was anything wrong with me so I thought that everyone must feel the way that I did. I was desperately ill and tired all the time and was constantly aching. I went to the doctors a few times, they said that I was working full time and that I was a mum – what did I expect? When I was promoted they told me that I was pushing myself too hard.

13. I became more and more unwell. By 2016 I had lost half of my body weight and was down to less than 7 stone which on a woman of 6ft tall looked terrible. I could not tolerate food and was being violently sick. Eventually I was referred to a Haematologist who I saw in around September 2016. He told me that he did not know what was wrong with me but that I might have blood cancer. He sent me for several tests.

14. One of the tests was for Hepatitis C. This test came back positive. My Haematologist told me that he thought that this was a false positive caused by my autoimmune disorders. I returned the following week for a second test.

15. A few days later I received a phone call from my GP who told me that he had received a letter and asked me to come in to see him. I went in that day and sat down in his room expecting him to discuss any one of my many conditions.

16. The first thing he did was hold up a letter which stated 'Public Health England' at the top. He said "I have to tell you that if you are a drug user and are sharing needles, or if you are a sex worker then you are a risk".

17. I went into shock and asked him "what have I got?" He told me that I had HCV. I had to ask him what that was and he told me that it was Hepatitis. I told him that this was not true, that I had had a test but that there had been a false positive. He did not explain that the second test had come back positive; he just held up the letter and told me how dangerous I was. He told me that I could have passed it to my children and my husband.

18. All I could think was that I had killed my kids. I did not know what HCV or Hepatitis was. I was shaking and crying. I told him that I had never done drugs and that I was not a sex worker. He said that there was still a risk I could pass the infection on. I asked the doctor if I was going to die. He just told me that I had to see a liver specialist.

19. I walked out of the doctor's surgery feeling suicidal. The last thing the Haematologist had told me was that the first test had probably been a false positive. I had not looked anything up about Hepatitis and did not know anything about it or what it meant for me. My GP had not told me what Hepatitis was or how it would affect me. All I could think was that I had something dangerous, that I was going to die and that I could not cope. I knew that there was a viaduct close by and I planned to drive there and throw myself off it.

20. To get to the viaduct I had to drive past my house. As I passed by I realised that I could not do this to the kids and I decided to go in and tell them. I still have flashbacks of that day; I can remember the doctor's room, the pen on his desk. I now have to avoid that GP and cannot see any other doctor in that room. I have recently been diagnosed with Post Traumatic Stress Disorder (PTSD).

21. Around 1 month later I went to see the Haematologist who was furious that the GP had told me the results before he had had a chance to speak to me about it. He wrote in a letter that he was seriously unhappy with the GP. The Haematologist told me that Hepatitis was a liver problem and that I would need to see a liver specialist. He told me that he did not have a full understanding of Hepatitis but that it was probably the cause of my problems.

22. I had to wait for weeks to see the liver specialist. When I eventually saw a specialist nurse at GRO-B Hospital she questioned me about my background. She asked whether I had ever had tattoos or piercings. She asked me to tell her about myself, I told her that I was married and had four kids and that I had had a blood transfusion in 1986. She said that this could be the route of infection but that she would send me for further tests.

23. I saw her again several weeks later. She told me that I had damage to my liver and that the extent of the damage fit with me being infected in around 1986. She told me that she would put me forward for treatment but she did not tell me anything further about Hepatitis C. She wrote down the names of the Skipton Fund and the Hepatitis C Trust on a piece of paper and told me that I should get in touch with them. I did not see her or any other specialist again until I started the treatment approximately 6 months later.

24. When my GP told me about the infection he should have explained what HCV was, what treatment was available, how it would affect me and what he was going to do to help me. All I was told was that I had it and that I was a danger to society. I honestly thought that it was another version of HIV; this was the way that it was explained to me. The way in which I was told about the infection was inhumane, and was mentally and emotionally damaging to me to the point that I nearly took my own life.

25. The only information that I was given by doctors about the risks of others being infected was that there was a risk if I shared needles, injected drugs or was a sex

worker. I was not told anything about the risk of passing the infection through cuts, nor was I given any practical information like avoiding sharing toothbrushes or razors. Instead I was told that I was a danger to society and probably had already passed the infection to my kids and my husband. I felt as if I had been given a death sentence and that I had probably killed everyone else too.

26. I have never been given any leaflets or print outs by my GP or the specialists that I have seen at the hospital. All the information I now have about the risk of passing the infection was given to me by the Hepatitis C Trust.

Section 3: Other Infections

27. I don't know whether I have been given any other infections. I found out recently through support groups about the risk that I may have also been given CJD. I know that they can't test for this until post mortem. When I found out about this I could not help but think that I have lived with Hepatitis C for 30 years without knowing, maybe this will be the next thing to rear its ugly head.

Section 4: Consent

28. The way that I was given the blood transfusion and then suddenly sent for an ultrasound scan seems very odd to me. I know that the medical notes for that day are missing, and that there is no record of the blood transfusion or of the ultrasound scan. Since finding out that I have Hepatitis C I have wondered whether they were deliberately infecting me that day. I was young and healthy, maybe they wanted to see what would happen.

29. Since the transfusion I have suffered from so many conditions which point to Hepatitis C. I have been seen by Haematologists, rheumatologists, gastroenterologists. I have had thyroid cancer and several miscarriages. Despite all of the conditions that I have been treated for, they did not pick it up for 30 years. I have asked doctors and nurses about this, they told me that I did not look

like an at risk person. I have no proof that I was treated or tested without knowing or without my consent but the lack of notes relating to my blood transfusion makes me feel uneasy.

Section 5: Impact

30. I am not who I was, who I could have been. I was a teenager when I was infected. I have not felt happy or well since 1987 and have existed for decades with exhaustion. Mentally it has dragged me down and has stolen who I am. Physically I am too tired, too ill, hurting too much. I feel I have had the life stolen out of me, that's the only way I can explain it.

31. I have lost my health, my job, my capabilities, my confidence. I was doing well and I could have had a good future ahead of me. I had been promoted at work from part time shelf stacker, to full time section leader, then stock control officer, then supervisor and key holder. I had just agreed to start management training when I became too physically and emotionally exhausted to work. I could have been on a good wage but it all stopped.

32. I gave up work in 1998, I was too ill to look after the children and so my husband had to give up work too. We have had to struggle on benefits for years instead of continuing in full time employment in jobs with good prospects. The infection has taken away our financial stability; it has taken away our chance of owning our own home.

33. Since 1987 I have suffered from lots of different conditions which I can now see are probably secondary to my Hepatitis infection. These include depression, irritable bowel syndrome, fibromyalgia, thyroid cancer, exhaustion, an enlarged spleen (which I was told was because I am a tall lady), and F3 liver fibrosis. In around 2003 I was told that I had a possible autoimmune disease, something was setting my immune system off. After numerous tests they could not work out which autoimmune disorder I had and eventually I was diagnosed with

Undifferentiated Connective Tissue Disease (UCTD). I have suffered several miscarriages including losing one twin on two occasions. I now have two half sets as two of my sons should have been born with a twin.

34. The way that I found out about my infection has caused me PTSD on top of everything else. I am glad that I don't drink; if I did I would not be here.

35. I had Epclusa to treat HCV for 12 weeks between August and October 2017. I was told 12 weeks after the end of the treatment that I had cleared the virus.

36. I had been told in January 2017 that I would be put forward for Epclusa but that I would have to wait for the funding to be approved. I was warned that it might take a while, my specialist nurse told me that she was due to retire in five years and that the treatment *may* happen before then. Every month the board confirmed who they would fund. Every month it could have been that month. I had to wait six months for my funding to be approved, the stress of this was unbearable. I thought I was going to die while I was waiting for the treatment.

37. My wait was shorter than others; I think that because I have Genotype 3a which is the more aggressive Hepatitis C, and that I have F3 Fibrosis I was bumped up the list. However I do not think that I should have had to wait for the treatment. I had been given the infection by the NHS so the treatment should have been made available straight away. I was not offered any support while I was waiting, I was not contacted by my GP or any other specialist for check-ups or anything. I was left in the wilderness. I still knew nothing about Hepatitis C, about how bad my condition was or what this meant for me. I got in touch with the Hepatitis C Trust for information and they told me about the support groups on Facebook. I found out more from support groups than from any medical professional.

38. I do not think that there were many other treatments available to me. My other conditions mean that there are a few treatments that I would not have been able to have. However I think that counselling should have been made available to me

straight away, as soon as I was told about the infection.

39. The Epclusa did knock me, I felt very dizzy and tired. I had ringing in my ears and massive mood swings. My hair turned a different colour, it went very yellow and then it just all broke off. This was very hard for me. My fingernails had broken too, my hair was the last thing I had and this destroyed my self confidence. I had waist long hair before I had the treatment and I lost it all. It is growing back but it is still frizzy and it is not right.

40. I still feel tired and am still hurting and aching. I do not know if this is because of the treatment but it is probably as much from long term infection and my autoimmune illness which has caused damage to my organs. I have only recently been able to tolerate food. I have lived on prescription nutritional supplement milkshakes for the last couple of years. I had to stop eating because I was being violently sick. They told me that this was to do with the liver damage and all of the organs having to fight and being so damaged. If I had not been able to tolerate the nutritional drinks I would have had to have been fed through a tube.

41. Before I was diagnosed with Hepatitis C I was having monthly blood tests. As soon as I had Hepatitis C on my notes I noticed a real difference in the way that I was treated when I went for tests. The phlebotomists are no longer chatty, they look at my notes, go and get gloves and look at me like I am something that they trod in. This is particularly hard when there are multiple cubicles with the curtains open and other patients see the phlebotomist go and get gloves. I feel like they are thinking that I have something that is catching. I have noticed that I am now the last on the list for biopsies. These things make you realise that you are being treated differently.

42. I haven't gone to the dentist since being diagnosed with Hepatitis C, after the attitude of the phlebotomists I haven't been able to face it. I fear the reaction from them when I have to write down my diagnosis, even though I am "cured" as they say.

43. My Hepatitis specialist nurse and consultant were understanding and helpful. However one of my other consultants, my rheumatologist, who I had seen regularly over the years stopped seeing me following my diagnosis and got another from their team to step in. My oncology team has also changed.

44. Some GPs have been unprofessional and unhelpful. One in particular who made me aware of the infection was mentally damaging. Most lacked knowledge, understanding and compassion regarding my diagnosis. One has tried to be helpful but seems to know less than I do and has actually said "you know more about it than I do". This does not help.

45. I am now untrusting of medical professionals. I have not been offered 6 monthly or yearly ultrasounds to check the damage to my liver. This is contributing to my anxiety as there seems to be no follow up plan

46. The impact on my private, family and social life is difficult to describe. As a family we have struggled; before I was told about the infection I was desperately ill and thought I was going to die. Then there was the trauma of being told about the infection in the way that I was. I have suffered flashbacks and panic attacks ever since. After the diagnosis the shock of it was awful. **GRO-C** I lost the plot. I felt like I didn't know who I was, I felt like I had been living a dangerous life for 30 years.

47. It has put pressure on all of us; it has caused stress in my relationship with my husband. It has put stress on my children. I have lost friends and there are family members that I no longer see. We don't have a social life, we don't see anyone. I have hated myself for years, this in itself has had an impact. If the kids want to do something I am too ill, too tired or can't afford it. I haven't been the wife, the mum, the sister, or the daughter that I could have been. All of these things have been taken from me and from my family.

48. I have recently had a serious issue with my neighbours. I was sent a letter by EIBSS, it had the correct address on it but was delivered to the wrong house. My neighbour opened the letter and found out that I have Hepatitis C.

49. I received an anonymous letter which stated my name and my EIBSS reference number. The things they wrote in that letter were absolutely vile and disgusting. They said that we had dirty blood and that they did not want people like us in their community. They said that people like us should be taken into a field and shot and then our bodies burned like a cull of cows and badgers.

50. I shredded the letter and got in touch with the Police but things got worse. Dead animals were thrown onto our drive; red sauce was squirted all over our van. It went on and on. I never found out who it was. We put a camera up but all that we could see were things being thrown at the house, not the person throwing them. We thought that it might be someone who works in pest control because of all of the dead rats, squirrels and birds that ended up on our drive. We were all terrified that the house would be burnt down. We were living in fear every moment.

51. A police officer said that she had seen similar incidents in the '80s with people who were targeted because they had AIDS. The police told us that we should move. I wrote to my MP and to the Council and explained that we had to be moved. We lived with the abuse for about five months until we left the area.

52. We moved house recently but I still jump at the slightest sound. **GRO-C**

GRO-C

53. This infection has affected all of us so badly. It has had a devastating impact.

Section 6: Treatment/Care/Support

54. I asked my GP to refer me for counselling in around February 2017. I said that I was suffering from anxiety and possibly from PTSD. I had to keep getting in touch with the GP, it was over a year before someone saw me. The GP was trying to persuade me to go to group counselling. I said that I did not feel comfortable with this. When I finally got an appointment with talking therapy, the person I saw was totally inappropriate. I started to explain my situation and she said "oh my god that is getting me stressed even listening to you". I went back to the GP and said that I needed to see someone else.

55. Eventually I saw someone else who then referred me on. I started seeing a regular therapist for cognitive behavioural therapy and EMDR. The therapy sessions available are limited to 10-12 per patient, I felt under pressure to be cured in this set number of sessions. I am not sure how anybody is meant to get over this and to be cured mentally and emotionally in a limited timescale especially with the ongoing Inquiry.

56. I saw her for around four weeks, however this was at the time that I was having problems with my neighbour and had to move. The limited number of sessions meant that I could not rearrange an appointment or put things on hold while I was moving house. The therapist told me that the move was getting in the way of the treatment and she discharged me. She said that I will have to go back to the GP to get referred again but that there should not be the same delay in being seen.

57. Now that I have been discharged I feel helpless, lost and scared. It is important to me that I give a witness statement but talking about it has brought it all up again. I have no one to talk to apart from my family who are themselves desperately impacted by the whole thing. I need someone outside it all. I will have to ask my GP to refer me back to Talking Therapy but I feel panicked that the therapy is not going to work in the limited sessions. I have tried to phone the Red Cross helpline set up by the Inquiry but the line is not always open. I have spoken to the

Samaritans a couple of times.

Section 7: Financial Assistance

58. I registered with the Skipton Fund as soon as I was told about it by the specialist liver nurse. This was in around December 2016.

59. I have found applying for assistance difficult, upsetting and frustrating. I gave the forms to my GP however after three weeks they gave the forms back to me and said that they did not know enough about how Hepatitis C affects people and told me that I would have to ask a specialist to fill them in.

60. I requested my medical records but had to wait months and months for a final response from the GRO-B NHS Foundation Trust (the Trust) which stated that key parts of my notes had been lost or destroyed. It then took time for the Hepatitis specialists to read the forms, read the notes that were available and then to complete the forms.

61. It is very upsetting that the fund will only pay when they finally get all of the necessary information and signatures, and not from the date that I first applied. I found out that I had Hepatitis in September 2016 and registered with the Skipton Fund in December 2016, however I did not receive payments until October 2017. Having found out I was infected in 1986 and diagnosed in 2016 it was nearly a year until I received any financial support. The payments should have been back dated until at least the date that I was diagnosed if not until the date that the scheme was set up. It is not my fault that I was infected or that it took 30 years for me to be diagnosed. I do not see why I should not receive payments from the date that the scheme started as others have who were diagnosed earlier.

62. I received the stage 1 lump sum payment from the Skipton Fund in October 2017, and then received monthly stage 1 payments. I have since applied for special category mechanism (SCM) payments which have been agreed. From April 2018

I have received income top ups from EIBSS. I also receive the winter fuel allowance.

63. I applied to EIBSS for funding for a specialist bed and provided a letter from my GP confirming that I suffer from severe joint and muscle pain. I had to pay £10 for the letter. My application was turned down; EIBSS said that this funding would not be granted unless a doctor stated that my symptoms are caused by Hepatitis C. My GP said that he could not write that Hepatitis C was definitely the cause; he said that he could give a probability but this would not be enough.

64. I felt really upset that this funding was not granted, especially after going to the trouble of making the application and paying for the GP letter. It is bad enough having to beg for things like this, let alone when they are not granted. The Hepatitis C is the cause of the painful conditions (such as fibromyalgia) but is not the cause of the pain itself and so I am not eligible for this funding. I cannot afford to buy a specialist mattress myself and as a result I am still in pain at night and my sleep is still affected.

65. I believe that the stages of the Skipton Fund are unfair, I should have received the stage 2 lump sum. I have severe fibrosis which is just under the F4 needed for Stage 2. Skipton have agreed to pay SCM which means that they accept that I am as badly affected as those who would qualify as stage 2. I have lived a healthy tee total not fat food life style which has probably saved me from cirrhosis but I feel that I have been punished for this financially.

66. The staff at Skipton were polite and helpful but I have had problems with some from the EIBSS constantly telling me conflicting information and being impatient when I questioned them on this. Other benefits staff seem to think HCV means that you just have an inflamed liver and after successful treatment you should be fine.

67. Personally I feel that I was left to die, and that I was not diagnosed earlier in order to save money. I believe that all of the support payments should be the

same UK wide and available to all without the stage system. Infected is infected.

68. Due to my ill health I have GRO-C lost a job and a career as well as the financial benefits including our own home, savings and pensions.

Section 8: Other Issues

69. When I applied to the Skipton fund I requested copies of my medical records but told that some were missing. There are no records for the day of my transfusion, 23rd May 1986. There are doctors notes for 19th, 20th, 21st, 22nd May and then for 24th May until I was discharged. There are no nursing notes for any part of the admission. There is nothing in my records which confirms that I had a blood transfusion on 23rd May 1986, or that I had an ultrasound scan on that day.

70. The discharge letter from my hospital admission in 1986 is ticked to say that I did not have anaemia. It is this that worries me most; I feel that the reason that I needed a blood transfusion has been hidden. It is as if they distorted the truth to cover up what they were doing. During all my other pregnancies my iron levels were so low that I was offered a transfusion. However after my transfusion in 1986 I did not want to have another and was treated with iron tablets instead. This was before I found out about being infected with Hepatitis C.

71. It was accepted by Skipton that given my iron levels during other pregnancies it was likely that it would have dropped during my first pregnancy, to the point that I would have required a transfusion.

72. I had to write a complaint to the Trust to get them to do a second search for my notes. They were quite offensive towards me until my local MP got involved to help encourage them to makes notes available or agree what had happened to them. Eventually in September 2017 the Trust agreed that my notes were missing. I exhibit the letter from the Trust dated 20.09.2017 **[WITN1921002]**. I now realise that some of my notes will never be available.

73. I want the Inquiry to make sure that we are de-stigmatised and to make sure the media and the public know that we are not trying to claim compensation from the NHS budget. We want to find out who was responsible and when they knew. I want to know whether those receiving contaminated blood as well as blood products were a random percentage or whether they were chosen as tests cases or not. Was I just unlucky or was I chosen as a Guinea pig?

74. In relation to medical notes that no longer exist, were they changed or destroyed at the time of infection or did someone go back to the records at a later date?

75. I want to know whether there was ever a list of those infected, if so does this list still exist or did they destroy it, literally leaving us to die.

76. I would like the Inquiry to recommend that criminal charges are brought against any individual that knowingly allowed people to be infected and anyone who tried to hide knowledge of this act at a later date. I think the Inquiry should ensure there is a process or a policy to stop any government department creating a similar situation in the future.

77. Finally I would like to Inquiry to recommend and ensure appropriate financial compensation is paid to all victims and their families.

Statement of Truth

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

Signed: GRO-B

Date: 27 November 2018