Witness Name: GRO-B
Statement No: WITN4338001
Exhibits: 0
Dated: 01.10.20

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 3 September 2020.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1953 and my address is known to the Inquiry.

2. I intend to speak about my infection with Hepatitis C (HCV) by blood transfusion. In particular, I intend to speak about the nature of my illness, how the illness affected me, the treatment I received and the impact it had on my family and our lives together.

3. I am not legally represented and I am happy for the Inquiry team investigators to assist me with my statement.

Section 2. How Infected

4. I was infected with HCV when I received a blood transfusion in 1975. This was when I gave birth to my first son, via caesarean.

5. When I was pregnant, my bump had been very big so the doctors thought I might have twins. I was X-rayed but it was just that the baby was very big. I was later told by a midwife that they should have seen that he was far too big for a normal birth.

6. On GRO-B 1975 I went into labour. I was 10 days overdue. I went to the GRO-B in London.

7. I went into labour on a Monday, but they didn't give me an emergency caesarian section until Wednesday at about 4pm, and that was only when the baby's heart was stopping. I had a really horrible experience. They cut me in a straight line from my belly button down. I had 12 metal clips and lots of stitches all the way down my stomach, this was on GRO-B GRO-B 1975.

8. After the caesarian, when I came to, I was encouraged to walk straight away. I went to the toilet and on my way back, the wound in my stomach opened and blood went everywhere. I thought I had ripped open, and the wound had ruptured open. I was terrified, I was screaming. It was horrific, you could see into my stomach.

9. They couldn't leave me in a ward with other people. I needed to be isolated because of the risk of infection due to the open wound. I remember being rushed to a private room and being given a blood transfusion. I think I had to sign something at some point before the caesarian. I was in a terrible state and got rushed off, there was no warning. I don't know how many units of blood I was given. I remember they told me that I was blood group O, which they didn't have and they had to get some.

10. I was put in isolation and I was hooked up to a drip of blood, for the transfusion. They said I was chronically anaemic because I was losing so much blood. They told me I couldn't breastfeed as I had lost so much blood and was anaemic. I was upset and disappointed that I was not able to give my son the best start in life. All in all, it was a horrendous ordeal. I have terrible scars to prove it.

11. The wound was very bad for some time, and I had to have radiation treatment every day to heal the wound and help it close. After 2 weeks of being in the hospital, I wanted to go home but they wanted to keep me in. Eventually, they let me home on the condition that I would come back every day for the radiation treatment. I did this for at least 2 or 3 weeks. My dad had to look after me, he would drive me every day to the hospital for treatment. I was unable to walk for about 6 months. It took that long for the wound to heal.

12. When I got home my partner nearly passed out when he saw the wound when I was changing the dressings. When the midwife came over, she said I should sue the hospital. She said the wound looked so bad.

13. She also said that when the x-ray had been done before I was due, they should have seen that the baby was clearly too big for my pelvis. The baby was too big to be born normally and should have been booked in for a caesarian in advance. Instead, I was left 10 days overdue, and then waited in hospital while in labour for 3 days! It was so bad. I feel that it was negligent on their part. She told me to prosecute the hospital for the way I was treated.

14. At the time, I was so ill that I couldn't walk. I also had a baby to look after. The last thing I could think about was prosecuting the hospital. I just wanted to get better. I wasn't going to go out of my way to sue them. I'm not like that I was just too ill. It would have added even more stress to my life at a time when I really didn't need it.

15. I lived in London at that time and about a year later, in 1976, we moved to Sussex.

16. 6 years later, in 1981, I got pregnant with my second son. We were living in GRO-B at the time. He was a big baby too, they both were and still are. They are tall as well.

17. The wound from my first birth hadn't healed into a normal scar. It was a mess, like a great big chasm down my stomach. The scar is now about 1 foot long and 4 inches wide. It is a huge, unsightly lesion.

18. On GRO-B 1981, I gave birth to my second son, at Sussex County Hospital. I had been booked in for a caesarian 2 weeks before he was due, because again it was a big baby. He weighed almost as much my first son weighed, and this was 2 weeks before the due date rather than 10 days after.

19. The night before the caesarian, the surgeon saw my scar and offered to neaten it up for me, to make it look better. But the following morning she suggested that a smaller transverse cut would heal faster than her repeating a vertical incision and trying to remove the old scar tissue. She said, "I can do it for you, but let's face it you'll probably never wear a bikini, and a small cut will be a lot quicker to heal." She said that there was a risk of longer healing time when opening up scar tissue. My partner said, "just have what is better for you, don't worry about other people. I don't care what it looks like, just do what is better for you." I had a small incision that time.

20. Later on, when I was going through the menopause, my scar tissue was a problem too. Initially the doctor considered me having a hysterectomy because I was haemorrhaging badly, but then he said that it would be a problem because I had such bad scar tissue. He wasn't keen on operating, as the old scarring would cause complications and make healing difficult. At the time, I had no idea I had been given infected blood, that came later.

21. In 1987, my late partner, died in very traumatic circumstances. It was very difficult, for both me and the boys. They lost their father unexpectedly. He had been missing for 3 days when his body was found on a train, in the toilet, and the cause of death has never been discovered. The inquest stated that he was a perfectly healthy man of 41 and according to the pathologist there was no indication of any natural or unnatural causes of death. The inquest recorded an open verdict.

22. After the inquest I went to my partner's GP to ask if he had had any illnesses that I didn't know about. He said he might have asphyxiated from the haemorrhage in his nose, or his heart might have just stopped, which wouldn't have shown up in the autopsy. Because there had been a lot of blood at the scene, as a result of him haemorrhaging, they had to test him for HIV and it came back negative. Also, when his autopsy was done they checked his liver and it was perfectly healthy. There was no mention of HCV, nor 'non A, non B' hepatitis as it was called at the time. The GP stated that he felt that as my partner was fit and well, that if he had been found earlier, he may not have died.

23. After the inquest, I was advised by a solicitor to ask for a review, because the death had not been dealt with in a timely and proper way. As stated at the inquest and by my partner's GP, he should have been found earlier by British Rail staff. They obviously had not searched or cleaned the train he was on. She advised me to prosecute British Rail for negligence, but it turned out that I couldn't get legal aid to request another inquest. She warned me, that if I pursued British Rail and lost the case with costs awarded against me, I could risk losing everything, including my house. I couldn't risk it. I had to let it go. I had small children to look after.

24. I didn't get any answers and I've had to live with it for 33 years. After he died, people would ask me how I cope without seeing a psychiatrist. I

would say, “I’m too busy, I don’t have time to think.” But I think it hits you later.

25.The kids have been very damaged by what happened. Every Christmas is very hard without him.

26.Financially it was very difficult. I found myself in a position having to support the children without his help. At the time I had a GRO-B shop with my mother, but that had to close down.

27.After my business failed, I wanted to work but as a single parent with 2 young children, I needed help with childcare costs. I didn’t want to live on benefits Manpower Services were offering to pay training and childcare costs. They said I needed to sign on as unemployed but because I had school aged children I was not eligible. What was I supposed to do? I was told, “it’s a catch 22 situation but it’s one of those things.”

28.I decided to do an access course in 1988, and then went to university and did a degree. I thought it would be better for my boys than me being unemployed. I wanted to set an example for them.

29.I wanted to do an Art Degree, like my access course but there wasn’t one locally. I’m half Italian and my dad used to tell me about Italy’s history and art, but I never listened when I was young. But later I wanted to study it. So I did my BA in European and Italian Studies GRO-B GRO-B

30.In 1995, my mum was becoming increasingly unwell and I moved to Devon to be nearer to her.

31.I had been working as a classroom assistant and began to like the idea of teaching. I decided to train to teach Design Technology. This was connected to my background in art. I did my teacher training at GRO-B and I started teaching in 1999.

32. In 2000, I was working full-time as a teacher. My mother got diagnosed with Alzheimer's and she was living on her own. After work I would stop off at hers to check on her, cook her dinner and put her to bed. Then I would go home at about 10pm to do the same for myself, and get up for work at 6am the following morning.

33. It was a very tiring time, but a few years later I was getting inexplicably more tired. I knew something wasn't right but I didn't know what it was. I think often HCV doesn't give you bad symptoms until it's too late.

34. I think it was sometime in 2006 that someone told me that they had tested positive for HCV and they described some of the symptoms. It sounded familiar. I had been having trouble with my digestion, and I generally didn't feel all that well at the time. But I didn't think it was possible that I had HCV. I thought, "there's no way I've got that." I wanted to get checked but I was sure the results would be negative.

35. When I asked my doctor to get tested for HCV, she was really surprised. I said, "I just wanted to rule it out because now it's in my head." She would never have tested me for it if I hadn't asked. But she saw to it straight away which was good.

36. The doctor did the test and later said, "I'm sorry to tell you, it's positive." She was as shocked as I was.

37. I don't know if I was tested for anything else then.

38. I had sort of figured it out myself. She would never have thought to test me for HCV if I hadn't asked. A similar thing happened years later when I had an issue with swelling ankles. I had been going to the doctor for advice but they didn't have any idea why my ankles were so swollen. I had been on tablets for my blood pressure for some time and I hadn't thought about it. But then I realised that one of the side effects of the tablets was swollen ankles. I stopped taking the medication and within 2 days the swelling went down completely. It was a bit ridiculous. I'd been

coming to see the doctor about the swelling ankles for 2 years and at no point did she think of that.

39. When the doctor diagnosed me with HCV, she didn't really give me any information. She referred me to Doctor Christie, a specialist at Exeter Hospital. I think I was referred within a month. Dr Christie put me in contact with a HCV nurse so that I could phone them if I had any questions.

40. I was not offered any counselling or other support.

41. There was no mention of my sons getting tested. They later did it off their own back because I was so worried. Neither of my sons were local at the time, but still they should have been advised to be safe. I could have given it to them in their childhood.

42. I think it was 2007 when I was referred to Dr Christie. He was sure that I had gotten the HCV from the blood transfusion in 1975. I had no idea about infected blood until then.

43. I haven't had any other transfusions. I have never used intravenous drugs and I don't have any tattoos. I had my ears pierced professionally.

44. I told Dr Christie that my late partner had used drugs in the past. I'm always honest. I'm too honest. But he ruled that out completely and said that in his opinion the blood transfusion was to blame. I also have evidence that he was clear of HCV since it was not in his autopsy after his death.

45. Dr Christie was convinced that the blood transfusion in 1975 was when I became infected. He told me about the Skipton Fund.

Section 3. Other Infections

46. As far as I am aware, I have had no other infections besides HCV.

47. I have not been told if I have been tested for HIV specifically but I assume that I have. The investigators have brought it to my attention and I plan to ask my doctor.

Section 4. Consent

48. I signed something when I was giving birth to my first son to authorise the doctors to carry out the caesarean and any necessary procedures, but I do not believe that I had informed consent of all potential eventualities, in the case of infected blood or infection due to negligence.

49. I don't believe I was tested on without being aware. I can't think of a time when I was given a test that I didn't know what it was.

Section 5. Impact

Physical and Mental impact of Hepatitis C

50. Before the HCV, I had good energy levels, but leading up to my diagnosis I had felt increasingly tired. I also had digestion issues and generally felt like something wasn't right.

51. My liver has been damaged as a result. When I had my liver tested before the treatment I was told I had a fatty liver but I didn't have cirrhosis. I did have some scarring. I think now my liver is quite delicate. If I have fatty food I can become quite ill.

52. The mental impact has been immense. I have suffered with depression for many years. I have had so much going on in my life.

53. There was no counselling offered at the point of diagnosis with HCV. I didn't ask for it either. Not only was I ill, I was caring for my mother and

my brother. My brother could be very challenging so there was quite a lot to negotiate at the time. It was not easy.

54. Even now there isn't much treatment on offer for depression. After my brother died in GRO-B 2016, I had some counselling but it wasn't very helpful. They just focused on the negative which I found really difficult. They said I probably needed bereavement counselling. I said I wanted to do CBT. They said that it wasn't meant for bereaved people. I wanted to try to move forward and do something positive to help myself.

Physical and mental impact of the treatment

55. About 2 or 3 months after I was diagnosed, I had my HCV treatment with Dr Christie at Exeter Hospital. He told me that I had genotype 3. What I understood from him was that this genotype was the most likely to be treatable. The other genotypes had treatment for a year but mine was 6 months.

56. He did a liver biopsy and assessed me to see if I was ok to have the treatment.

57. He put me on the combination treatment - Ribavirin and Interferon. I would have a Ribavirin tablet once a day, and an Interferon injection once a week. That was a real problem for me because I hate injections. I had to pick them up at the hospital and leave them with the nurse at the Doctor's Surgery, so that she could do them for me. She would keep them in the fridge and I would come in every week.

58. Those 6 months were hell. I was so sick. I could hardly get out of bed, I felt like I was 100 years old. All my bones hurt, I ached all over, it was a weird feeling. I felt sick all the time. I was exhausted. I felt really old and incredibly ill. Everything was an effort, it was unbelievable.

59.During the treatment I lost so much weight. I lost a couple of stone. I was always being sick. I couldn't eat. The only thing I could manage to keep down was porridge or rice.

60.Another issue was that I couldn't sleep. I'd be awake for most of the night and when I would sleep I would have terrible nightmares.

61.The Ribavirin didn't make me feel great but it was nothing compared to the Interferon. On the 6th day, I would just about start feeling better and then on the 7th day I would get the injection and feel awful again.

62.I can't tell you how hard it was. I couldn't work, it was all too much. The doctor might have warned me, but you don't realise how extreme it is until it happens to you.

63.People who know me said I looked like the walking dead. There was no life in my eyes. I did the 6 months of treatment though - I had to.

64.Every couple of weeks I would have tests, then it was once a month. My bilirubin levels went very high. The doctors were worried, they weren't sure I would be able to carry on. My health became very bad.

65.Those 6 months of treatment were hell. I had a friend who couldn't complete the same treatment. The only reason I kept on is because I wanted to keep living. I had my children. If I didn't go through this then I would be even more ill later on. I knew this was the only way to fight it.

66.I had reasons to live for. I'm very driven, I've always had this mindset. I'm quite a determined person so if I have a goal, I'll go for it. I've done a lot in my life. I was an unqualified candidate when I applied for university. After my interview I was offered an unconditional place and I didn't have to finish my access course but I decided to see it through and finish it. I am very determined person.

67. I had to go to Exeter Hospital by bus once a month to see Dr Christie and get my medication. There was an impact physically, emotionally, financially and time wise. And I was so ill when I was doing the journey. It was a 1.5 hour bus ride to get there, and £3 each way. It was awful being on the bus when I was so ill. That was traumatic in itself.

68. When choosing hospitals, I had the option GRO-B or Exeter. But there was no bus to GRO-B and it's up a big hill. I knew I couldn't do that, so Exeter was the best option. But I don't know why I had to get there myself while I was ill. Even if I had had a car, it would have been even more expensive.

69. It was 6 horrendous months. I had weekly, then monthly blood tests during treatment. I then had blood tests 3 months after completing the treatment, and another after 6 months. The post treatment tests were all negative. I've never been offered a test since so I assume I'm all clear.

70. After the treatment I have had liver problems, gall stones and really bad digestion issues. The doctor said the gall stones were definitely related to the treatment.

71. I now have a bad reaction to some foods, I often feel really uncomfortable. I tried giving up different foods and that's when I realised I was lactose intolerant. Within half an hour of accidentally having milk, I will know because I'll be really ill. This intolerance is also as a result of the treatment. I think it's all connected to the digestive system and bilirubin levels.

72. I'm told I am "prediabetic" now, but I assume that is to do with my weight. I think I eat healthily but I can't seem to shift my weight. It might be something to do with me not sleeping at night.

73. I've been through a lot. I looked after my mum for 17 years, even whilst I was having treatment, and I was so ill. I have no idea how I got out of bed to do it. In a way it's what got me through because I had to do it.

But to be ill and be coping with my mum at the same time; it was hard. She couldn't be left on her own for 5 minutes. I wasn't doing much back then, just existing and trying to look after my mother.

74. I would cook for my brother and mother every day, even though I couldn't stomach the food myself. I have since lost them both. I had to look after my brother for 11 months when he got lung cancer. Exactly a year later my mum died.

Impact on Family Members

75. It affected both of my sons and my whole family as well.

76. At the time I felt a bit like a leper, I didn't know much about it. I was so scared of giving it to my children. As far as I understand it, it is passed from blood to blood. I was so scared I would pass it on to my family.

77. My younger son could have had it since birth. I couldn't understand how he was ok. The doctors told me it was because of the caesarian. He was in the womb so he wasn't exposed.

78. The boys were tested as adults and did not have it.

Financial Impact

79. I really struggled financially. I had to give up my work. I couldn't manage teaching when I was ill. When I started the treatment I was working part-time, doing supply teaching, but then I wasn't able to.

80. It was terrible financially. I had to apply for benefits. The weekly amount I got was about half of what I got for a day of teaching. I got £50 per week as opposed to £500. I did not manage. I've been riddled with debt ever since.

81. I only get £48 a month teachers' pension now as a result of giving up work early.

Stigma

82. I told my children and quite a lot of my friends. People do treat you differently. I was working at the school so it was problematic. They didn't react well, that was a bit extreme. People were worried that they were going to catch it from me. They would worry about cuts.

83. In 2011, after my treatment, I did a 'Return to Teaching' course where they place you in schools. I told them that I had already had the treatment and got the 'all clear' but I still got treated the same way, as if I had it. People thought I was contaminated. I had to go through Occupational Health and satisfy criteria that I was not a risk to other people (students and staff). This was humiliating and upsetting.

Section 6. Treatment/Care/Support

84. Dr Christie was a very good doctor. He was a very nice man, very supportive. I think I got good treatment but I thought there should be some after-care support. When I got the 'all clear', that was it. I didn't get any support after the treatment. It took me months to get over the drugs. And there's all the mental stuff as well which there was no support with. I never had any counselling offered.

Section 7. Financial Assistance

85. My friend kept telling me to apply to the Skipton Fund, and I put it off for ages. Then Dr Christie suggested it again and I did apply.

86. I made an application in 2008 but then there was a delay with signing it off, which wasn't until 2010. I must have been so ill that I shelved it. I felt so sick from the drugs that I probably didn't want to deal with it at the

time. Plus I was looking after my mum who had Alzheimer's very badly by then. I think there was also an issue with my doctor initially not having completed the form properly, so Skipton were not able to process the application for some time.

87.When I went to my doctor, and asked for my medical notes, she gave me some records but strangely *just* the notes for the relevant period were missing. I can't believe that. She wrote a letter to the Skipton Fund confirming this.

88.I was also told that the GRO-B Hospital where I had my transfusion closed down in 1992. And the Blood Transfusion Service apparently destroy all records after 7 years. I find it quite weird. My doctor had all this paperwork from god knows when but not from the time that I needed evidence of.

89.In 2010 I was denied support from the Skipton Fund because there were no medical records available to confirm that I had had a blood transfusion. This was the case even though I had sent in a supporting letter from my GP where she pointed out that there was a handwritten note mentioning missing documents, which may well have contained details about the transfusion. Despite this, my application was declined.

90.The doctor had also disclosed that my previous partner had used drugs which was seen as an additional risk factor and a reason for them to assume I had gotten HCV elsewhere. But I think this detail about him was just an excuse for them to avoid paying me anything.

91.I should have appealed and I didn't. There is evidence I didn't use. My partner was clear of HCV and I have evidence of that in his autopsy. They had tested his liver specifically and it didn't have any mention of HCV. The autopsy says his liver was in good condition.

92.There was definitely an impact of Skipton blaming me and making me feel like I hadn't gotten HCV from the blood transfusion. I feel very disappointed about the medical records too. I find it amazing because specifically the years I needed records of were not there.

93. I did not know about EIBSS but the investigator has informed me.

Section 8. Other Issues

94. With the traumatic emergency caesarian and resultant blood transfusion, subsequent HCV infection and Skipton refusal, I feel like all these bad medical things have happened to me and I've never had any recourse.

95. When I gave birth to my son, I couldn't have imagined that I would be given blood that would make me ill? You'd think it would have been screened.

96. I do wonder about my medical records. I wonder if the hospital was worried about me suing them and didn't give them to me for that reason.

97. For myself and for people like me, it has impacted so much on our lives. It has caused so much suffering. If I hadn't had that infected blood I would have been much fitter and able to cope. It completely changed my life for the worse.

98. If I hadn't found out about the HCV and gotten the treatment, I don't think I would be here today.

Statement of Truth

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

Signed GRO-B

Dated _____01.10.20_______________________