Witness Name: GRO-B
Statement No: WITN1853001
Exhibits: WITN1853002-5
Dated: August 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B. I was born on the GRO-B 1949. I am married to my very understanding wife GRO-B and we have two sons, who are 38 and 39, as well as six grandchildren. I am a retired GRO-B, I retired in 1992.

2. I am aware GRO-B will also be providing a statement to the Inquiry.

3. This witness statement has been prepared without the benefit of access to my full medical records.

Section 2. How infected

4. I have mild Haemophilia A. I was diagnosed when I was around 12 years old. I had some teeth extracted and they couldnot stop the bleeding after the procedure. They kept packing the bleedin my mouth with 'gold dust' in an attempt to stop the bleeding which didnot work. In the end they had to fly a specialist to the hospital to help. I received 36 stitches in my mouth but the bleeding continued. To stop the bleeding they filled the wounds in my mouth with hot tar. I remember they strapped me down so I couldnot move and once they put the tar in my mouth they then bandaged my mouth shut until the tar settled. I then had to eat tripe in order for my gums to heal. Following this dreadful incident I was diagnosed with Haemophilia.

5. As my Haemophilia was classed as mild I didnot require regular blood products. Most of the time GRO-B would dress my bleeds. It was only when I had bleeds in my joints or when I required surgery that I needed blood products. I was given a green card to show my status as a haemophiliac.

6. I received blood products throughout the 1970s and 1980s. In 1973, 1975, 1982 and 1983 I received cryoprecipitate, Factor VIII and DDVAP treatment for bleeds. In 1982 I was admitted to hospital from work due to a bleed into my knee and I received Factor VIII treatment. I do not have medical records to show batch records in respect of the Factor VIII concentrate treatment I received but I attach at exhibit WITN1853002 copies of my patient treatment card showing the batch numbers for the cryoprecipitate given. Within the same exhibit is a copy of my treatment record for 16th November 1982.

7. When I had a vasectomy in 1982 I was meant to be discharged after one day. However, I was kept in the Royal Victoria Infirmary (RVI) in Newcastle for a week due to complications following the operation.

8. I received all of my treatment in RVI, under the care of Doctor Peter Jones, Sister Maureen Ferns and Peter Hamilton.

9. I was never told that the blood products I received could potentially be dangerous or carry any infections, I wasnot told anything. If the risks had been explained to me beforehand I would have made other choices that were safer and available at the time. None of the procedures that I received blood products for were life saving or imperative. For example, instead of having a vasectomy GRO-B could have had a tubal ligation. This is one of the worst parts of this whole ordeal, it could have been avoided.

10. As a result of receiving contaminated blood products I have been infected with Hepatitis C (HCV) which was initially calledHepatitis Non A - Non B.

11. In the late 1980s I went on holiday and became very ill. I was in a lot of pain and was constantly vomiting. At first GRO-B and I believed I had food poisoning. However the illness persisted and my condition became worse even when we returned from our holiday. I was always tired and drained. I was working as much as I could at the time so I believed all these symptoms were a result of stress and overworking. This went on for a long time. Looking back I donot know how I lasted as long as I did feeling this way. I had constant pain in my back I would have to strap hot water bottles to myself just to get through the day. I couldnot afford to be absent from work as I had to pay the mortgage on my house.

12. In 1987 I developed jaundice. My skin had become yellow and this should have been a warning sign to medical professionals that I had an issue with my liver.

13. We had a family friend who worked in health insurance. He said he might be able to get us insurance and arranged a free medical. However, when the results of the medical became available they showed that I had an enlarged liver. It was actually very fortunate that this happened because it led to me making an

appointment with my GP in order to investigate my liver. My GP referred me to the RVI where I came under the care of liver specialist Peter Jones.

14. In August 1992 I had tests to investigate the issue with my liver at the RVI. After undergoing various tests I was told that they needed to speak to me and GRO-B. They asked us to return on the Friday morning, two days later.

15. When we arrived on the Friday the medical professionals were very formal in the way that they were addressing us. This was completely out of the ordinary. There was a really nice nurse who we knew who looked after us. She pulled us to one side before the appointment and told us that she had been in a meeting the previous week with her colleagues and they had been discussing different cases. She told me 'your name came up; they said you have Non-A Non-B hepatitis'. She asked me not to say anything as she would lose her job.

16. We were taken into a room with Dr Jones, Sister Fearne, Dr Hamilton and GRO-D GRO-D and I was asked how I was GRO-B said we had heard a rumour about HCV. They explained to me that I had Non-A Non-B Hepatitis and they were calling it Hepatitis C. When they told us it was very matter of fact, it was made out that the infection wasnot something serious and that it could just be treated with a couple of tablets. It did not dawn on us until later on, when GRO-B started researching HCV, how dangerous the infection actually is.

17. At first, I was quite relieved. I was scared I had AIDS prior to the meeting as there had been a lot in the news about haemophiliacs being infected by contaminated blood.

18. When we returned home and GRO-B researched HCV we began to realise that the infection was probably the cause of the terrible night sweats, tiredness, aches, shivers, flu like symptoms and more that I had been suffering from. We also looked into diet and herbal remedies to see if that could assist.

19. Beforehand the diagnosis I only went to the RVI twice a year unless there I had a problem such as an injury. Once I was told I had HCV my blood was regularly tested.

20. I donot believe adequate information was provided to me in order for me to understand and manage the infection. They only really told me to avoid fatty foods and to cut down on alcohol that was basically it. At some point I was sent a video that contained information on HCV but it wasnot what I would call adequate.

21. I believe the information should have been provided to me earlier than it was. I believe they had known that something was wrong a while before I was told. It was clear by this point that haemophiliacs were at high risk of having received contaminated blood. My doctors were well aware that I was a haemophiliac and that I had received blood products in the window in which I was at risk of having been contaminated but I was never called in for tests or given any information.

22. I was not given any information as to the risk of transmission. GRO-B found out most information about HCV from the TV and from Google. I am not sure if GRO-B or our children were ever even offered a test to ensure they had not been infected. In my view, this shows they did not have any regard for me or my family or our well being despite the fact they had given me infected blood products.

23. In around August 1993, we contacted the GRO-B Community Health Council and explained to them what had happened and they drafted a letter for me to sendto the Chief Executive of the RVI. There is now produced and shown to me marked WITN1853003 a copy of the letter written to the Chief Executive.

24 GRO-B was very angry at the time. We felt completely let down by those who were supposed to care for me. This could have all been avoided.

25. The letter at WITN1853003 is proof that we hadnot been given adequate information and didnot know enough about HCV. I did not receive a reply to the letter.

26 GRO-B and I wanted to take legal action but we were concerned about the costs we would incur. The solicitors we approached told us it would be almost impossible to take on the NHS.

Section 3. Other Infections

27. As far as I know I have only been infected with HCV.

28. I received a letter in the early 2000s saying that I may have been exposed to CJD. I remember saying 'oh well that's great'. It is something I couldnot do much about.

Section 4. Consent

29. I am not sure if I was treated or tested without my knowledge, I wasnot really ever told what they were doing. However, I do have medical records that show I was tested in 1985 for HIV which is now produced and shown to me marked WITN1853004. This was seven years before I was actually told I had HCV so they must have been looking for something at the time. The record states I have mild haemophilia and that I am "<u>UNTESTED</u>" for HIV. I never knew of this until I received my medical records.

30. Also from my medical records it seems that I was being tested for HIV without my knowledge There is now produced and shown to me marked WITN1853005

correspondence in November 1987 and August 1988 referring tomy test results. It appears Peter Jones knew I had HCV in November 1987yet I was never told anything. It makes me wonder what the intentions of those who were supposed to care for me actually were.

31. If I was tested or treated for infections before 1992 then it was without my consent and without having received adequate or full information.

32. I do not know if I was ever tested for the purposes of research.

Section 5. Impact of the Infection

33. Once I realised the implications of HCV, mentally, I was destroyed. I was relieved at first because I didnot have AIDS but I started getting angrier and angrier as time went by and I realised the true implications of the virus I had been infected with. I was very angry at what had been done to me.

34. I was worrying all the time. I didnot tell GRO-B but I was really concerned and was constantly wondering what was going to happen to me. I had to go to the RVI more often and they would take more blood every time and would ask how I was.

35. I felt very unwell physically. I felt I had constant flu and I constantly had really bad pins and needles. My eyeballs would feel that they were going to pop out of my head. My skin was so itchy, I would scratch so much that my skin would break. I still get some of the symptoms now being the pain and the itchiness.

36. At the moment I take 175 tablets a week for all the issues I have. I was told that I could have been offered better treatment for my illnesses if I didnot have HCV. I

also use heat patches for pain as well as morphine tablets and other strong pain killers.

37. I have many further medical complications as a result of HCV infection. I have developed skin cancer, type two diabetes, problems with my joints, I have an underactive thyroid and have had kidney stones on multiple occasions which have been treated with stents.

38. I have developed Osteoarthritis. At first doctors believed I had Psoriatic Arthritis but after I started having issues with my hips, I was tested and it was determined I have Osteoarthritis.

39. Also as a result of my infection I developed cirrhosis of the liver which led in 2008 to Hepatocellur carcinoma (liver cancer). As a result I was treated with Transarterial Chemoembolization which is a type of chemotherapy that targets the tumour. I also received Radiofrequency ablation (radiotherapy) to treat thetwo centimetre tumour. I was left bruised and sore.

40. In the end, as the treatment had failed,I was told I required a liver transplant and was placed on the list but I had to wait a year for it. It was very stressful waiting for that all important call which I received in 2009. When I had the transplant in June 2009 I was told that I had received it 'just in time'. After I received the transplant I was required to take anti-immune suppressants.

41. I had a lot of complications following the transplant. I returned to hospital in August of 2009 after the transplant as I had developed renal failure and abdominal pains. In September I developed a fever and septicaemia because the stent was infected, this developed into acute sepsis. On 6th October 2010 I had the infected biliary stent removed.

42. I had several forms of medication to try and cure me of HCV. In 1992/1993I had a liver biopsy followed by Interferon monotherapy. I had six months of treatment

at a high dosage and then a reduced dosage for a further 6 months twice per week. Unfortunately the treatment failed and I still had the virus after the year of treatment.

43. I was not given any further treatment for HCV until June 2003, 10 years after my first lot of treatment. I was given Virafon Pegulated Alpha Interferon and Ribavirin, 600ml. The Interferon came in the form of injection and the Ribavirin in tablet form. I taught myself to inject the interferon at this point as the there were such drastic side effects I found it difficult to make it to the RVI every time. I only lasted 5 months on this combination therapy as the side effects were too severe.

44. In 2006 when I was on Viraferon Pegulated Interferon I administered the injections myself but my skin was like leather and I found it difficult to get the needle in. On one occasion my nurse went on holiday and I became quite unwell. There was nobody to help and I ended up with pneumonia, I almost died. GRO-B had to stop the treatment.

45. In November 2011 I was in hospital again due to abdominal pain. In February 2012 I was taken to Freeman Hospital for pain management. In 2013 I had another liver biopsy and lots of kidney stones which required treatment. In February 2014 I had a hernia that was getting bigger and bigger so I needed surgery to fix this, they had to use mesh in the surgery. Later that year I had another liver biopsy when it was discovered my liver function was deranged. In April 2015 I underwent an endoscopy as I feeling sick. I had another liver biopsy in 2018.

46. My doctor told me that all of these problems are connected to my issues with my liver. My liver has to work harder which results in issues like kidney stones. it also means it is causing stress to other organs and as they were working harder it created further issues.

47. In 2017 I was given a course of Epclusa I believe it was only a 12 week course. I cleared HCVas result of the treatment. I had to keep having my blood checked for a year to ensure I stayed clear. As of May 2018 I have been declared free of HCV.

48. I am relieved I no longer have HCV but it is not without damage to my body and mind. I am on a cocktail of tablets all of which have various side effects: upset stomachs, headaches, brain fog, tiredness is still there; nowadays I cannot walk and use a wheelchair.

49. I remember when I was first diagnosed with HCV they tried to blame my issues on alcohol. They effectively tried to absolve the blame and make me think it was my fault which is completely unacceptable.

50. I have faced complications as a result of my infection. In the late 1980s/early 1990s I received dental treatment from dental hospital at the RVI.Whenever I would receive any treatment the medical professionals would always be masked and gowned. I would always be placed in a separate room at the end of the ward so that I was separated from other patients. It didnot dawn on me until later that this was because of my infection.

51. I recall there were hazard stickers on some notes and on another occasion when I was having skin cancer removed at the RVI we were asked to sit in a tiny room, it had a sink and just enough room for two chairs. We knew it was as a result of my HCV condition.

52. I was also made to feel bad about my infection as if it was somehow my fault. However, I am now treated a lot better than they did when I was first diagnosed with HCV.

53. I believe that I should have been offered my second course of treatment earlier than I was. There was a 10 year period when I received no medication at all.

They stated this was because of the genotype that I had but it was never really explained to me and I believe the lack of treatment caused my condition to worsen.

54 GRO-B did a lot of research intoHCV, I remember one doctor called her the 'Google Queen'. I believe it was the fact she was so proactive and constantly questioned and pushed them to give me treatment that led to me actually receiving more treatment and medication.

55. I am not sure whether there were treatments that ought to have been made available to me. GRO-B did inquire about Epclusa which ended up being the drug that cured me. So I possibly should have been given this earlier.

56. The mental and physical effects of the treatments I received were dreadful. In 1992/93 when I taking Interferon monotherapyI suffered from depression, weight loss and terrible nightmares. The nightmares were awful I had never had anything like them before. On one occasion I woke up screaming that there were rats in the bed, I nearly had a heart attack. Another time I had a nightmare that roman soldiers were marching into our back garden. I never had issues like this before I started treatment for HCV.

57. I developed a really bad temper and mood swings, night sweats, I was very low, aggressive and snappy and I felt sick. The effects became worse and worse the more Interferon I received.

58. I had no side effects for the final treatment I received, it was relatively straightforward.

59. I have also had extreme bouts of depression over the years especially when I was on Interferon. I used to feel useless, I lost my sex drive, I could do nothing to help GRO-B as I did not feel well enough to do anything with my family. I would shut myself in my bedroom, I did not want to see or speak to anyone and I

lost my appetite. GRO-B would try and make me eat and give me tablets and injections. I felt so lousy I would be really horrible and nasty to her. At one stage she talked about leaving me, fortunately she stuck by me through thick and thin and believe me she has had to deal with a lot. So have our sons. My family have kept me alive.

60. I wouldnot say my infected status has impacted upon the treatment I received but I would say that any treatment I ever did get was treated with extreme caution. I guess this is understandable.

61 GRO-B and I havevery little social life as a result of my infection, it went out the window. We only told a couple of friends and our parents that I had HCV, other than that we didnot tell anyone. However people knew I had Haemophilia and when the news featured Haemophiliacs being infected with contaminated blood friends started to assume that I had been infected.

62. One of our close neighbours used to also attend the same hospital as me and saw me there regularly. People started to figure out or assume I was one of the Haemophiliacs who had been infected and as a result our friends fell away. It was very hard to deal with; people we cared about just left us.

63. I would say I have lost years of valuable time with GRO-B, our children and grandchildren. Even at our son's wedding,while I was able to attend the ceremonyI was unable to join the reception. I more or less just said 'Hello' and went to bed. I had to leave GRO-B to mingle, I was too tired

64. We cannot plan anything or book ahead as I never know how I am going to feel.

65. We never really spoke to our sons about my infection although we told them not to tell anyone about my infection or mention it at school. We put my ailments down to my Haemophilia. If we ever had parties for the children GRO-B would be obsessive when it came to cleaning. We know that HCV is not transmittable

through sharing cups or anything of that nature but we couldnot trust any of the information we received through medical professionals. GRO-B would bleach, sterilise, boil and destroy things to stop any possible chance of transmitting my virus.

66. We told the boys properly when they were in their teens, we kept them sheltered. They had started to realise that something was wrong because we asked them not to share any information about me to anyone else. When we informed them we explained to them how important it was not to let anyone else know. We have seen so many families destroyed by it. People would throw eggs and harass people who were infected until they had to move homes. We didnot want this to happen.

67. Our sons are now in their late 30s and they now realise how bad it was for GRO-B and I.

68. I am lucky to have two hours sleep a night. When I wake up I feel fully revitalised but by 5pm I am completely exhausted. I watch TV in the night and rest in the day. There is nothing I can do about it, I have no energy or strength.I can not sleep any more than I do no matter how hard I try. I lost my appetite and went from 14 stone in weight to 11 stone. I used to be as fit as a fiddle which makes it all the harder to accept.

69. As a result of all the steroids I have had to take my skin is wafer thin, it breaks and bruises very easily. This results in a lot of cuts on my arm. I remember on one occasion I went somewhere and it was thought I self harmed because of the marks on my arms. The doctors told me that the treatment available to me was limited because of my Haemophilia and HCV. They did not even want to give me a general anaesthetic when they needed to replace a joint due to the potential affects on me. I am high risk of infection due to my low immune system; anti rejection tablets have lowered my immune system.

70. I have to be very careful in the sunlight and cover up. I use factor 50 sun protection as the anti rejection tablets have made me susceptible to skin cancers.

71. After I had my liver transplant I had a bag attached to me collecting bodily fluids. One night the bag burst flooding the mattress which became sodden. I called the Council to take it away and GRO-B explained I had HCV as I was worried about others being infected. They arrived in a huge truck with a big 'Bio Hazard' sign on it and they parked right outside my house. They came in to the house wearing masks and hazard suits, cut the mattress up, put it in plastic bags and took it away. They werenot discreet about it and some of the neighbours must have seen and I felt really contaminated.

72. As GRO-B and I kept my condition largely to ourselves we didnot face any stigma. We were aware however that it was a possibility at any given time.

73. We stopped going on holidays. I had bad experiences every time I flew, my legs would swell up. Plus it was impossible to get travel insurance as a result of my infection. We bought a caravan with some of the money we received. This is the closest we get to a holiday anymore. It is kept around 25 miles away from where we currently live. It is near enough a hospital in case anything happens but still allows us some time to relax.

74. I missed a lot of work as a result of having to go back and forth to hospital appointments constantly. I was made redundant in October 1992. I would have liked to carry on working, I liked working, but it is impossible due to the affect HCV has had on me. I can categorically state that I would have returned to work if it wasnot for HCV. I could have managed to work with Haemophilia as I did till I was in my early 40s. I had to have so much time off work for various blood tests and liver function tests.

75. The years of stress through lack of money affected my mood swings and ill health. All the paperwork filling in countless forms for ESA, Mobility Allowance and PIP then being rejected and having to appeal have all taken their toll. I was made redundant in November 1992 and money was tight, we were paying a mortgage and we struggled for years.We were lucky that GRO-B 's mother and father were in a position to help us whenever we were in financial difficulty.But for GRO-B 's parents in the beginning it would have been a real struggle.

76. GRO-B has had to work in various part time jobs in order to help support the family. When we first met she worked for GRO-B but she stopped working when we had children. She also worked for GRO-B, in a GRO-B shop and at GRO-B 's. She was also a part time payroll administrator in a GRO-B company before her retirement in her late 50s.

77. GRO-B has had to deal with depression as a result of my infection as well as stress and panic attacks. She has dizzy spells and is currently under GRO-B Hospital having her blood pressure and heart checked I know that she has spent a lot of time worrying about me.After she had seen the heart consultant she was prescribed beta blockers, statins and aspirin. The heart consultant advised her that stress could be a factor to her condition. Also her parents developed Alzheimer and she has had to care for them as well.

78. Also my children have missed out a lot as I havenot been able to do things that other fathers can as a result of the infection.

Section 6. Treatment/care/support

79. I have had several psychiatrists, probably about five one being GRO-B from GRO-B University who I saw in the 1990s. I also saw two other councilors at the RVI. After this I saw a therapist named GRO-B, this was paid for

by the Caxton Fund. I also saw a psychologist around a year or two ago through the MIND charity.

80. It was always difficult to get any help. I havenot always had the best experiences I remember on one occasion one of my councilors fell asleep while I was explaining the issues I had to him.

81. I found it helpful but I felt I needed more or longer sessions as I always felt that they were always in a rush to go to someone else, I only had an hour session at the time.

82. When I was on Interferon I felt suicidal. I wanted to drive off a cliff and sometimes wondered what would happen if I took all the tablets I had at once. GRO-B believes this was the worse stage of the depression that I went through. She was close to leaving me at this stage because I wasnot myself anymore. I could be really nasty and I required a lot of help. I couldnot do anything; I couldnot even make my own way to the toilet.

Section 7. Financial Assistance

83 GRO-B registered me with the Skipton Fund having heard about it throughthe Liver North Patient Support leaflet that we received.We learnt about the possibility of financial assistance and applied for it. The hospital helped with the application and completed the forms.

84. I received the Stage 1 payment of £20,000from the Skipton Fund in September 2004. In 2005 I developed cirrhosis and applied for the Stage 2 payment. Dr Agarwell confirmed my diagnosis and I received a payment of £25,000. In 2011 I received another £25,000 and in the same year the annual payment scheme commenced so I feel a little more secure.

85. I also now have in place, through the Skipton Fund, a pre-paid funeral plan.

86. Neil Bateman of the Skipton Fund was very helpful, he helped us to complete the ESA forms in 2013 and the PIP forms in 2016

87. The process of applying for financial assistance was not too bad once I found out that it was available. However if you wanted to speak to anyone at the Skipton Fund through the telephone it was a problem.

88. As far as I can remember there were no preconditions imposed whenI madethe application forfinancial assistance.

89. I do think that the Skipton Fund should have made HCV victims more aware of what they offered for example with help to purchase household goods, respite breaks etc. We did not realise this until about five years ago. We never applied for breaks or household items as we could manage with the annual payments other victims had greater need of the funds.

Section 8. Other Issues

90. I remember the doctors were difficult when I was trying to get my medical records for the first time in 1993/94 but when I asked again for my records in 2015 the Freeman Hospital were ok with my request although I had to pay a fee.

Section 9. Anonymity, disclosure and redaction

91. I confirm that I do wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

92. I do not wish to be called to give oral evidence to the Inquiry.

Statement of Truth

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

Signed... GRO-B ....

GRO-B

Dated: 22/08/ 2019