Witness Name: GRO-B
Statement No: WITN0056001
Exhibits: N/A
Dated: 4th December 2018

================================

STATEMENT OF GRO-B

================================

I, GRO-B
GRO-B will say as follow:-

1. I make this statement in response to an invitation from the Chair of the Infected Blood Inquiry and in order to assist the Inquiry with their investigations.

Section 1: Introduction

2. I was born on GRO-B 1949. I have been married for approximately 40 years and live with my wife in GRO-B We have three grown up children. I have spent most of my working life in the financial services profession and over the years have set up and directed various financial services companies.

3. My wife and I currently own and run an employee benefits business and claims management business specialising in pensions.

Section 2: How Infected

4. When I was approximately 21 I was diagnosed with aortic stenosis, which is a disease of the heart valves. At that time there was no treatment for the condition and I was told I would be in a wheelchair by the time I was 25 and dead by 30.

5. Thankfully by the late 1970s, physicians had developed a procedure whereby you could replace aortic valves. This treatment was still very much experimental at the time.

6. On 20 October 1978 I underwent an aortic valve replacement at St Thomas' Hospital in South London. My valve was replaced with a pig's heart valve.

7. On 31 October 1988 I underwent a further aortic valve replacement at the GRO-B which at the time was in GRO-B London, GRO-B This time the replacement was made out of titanium. This is still in situ.

8. I recall being told after each operation that I had had routine blood transfusions for the use of a heart – lung machine. The heart lung machine takes over the heart and lung functions during heart surgery where the heart is stopped and circa 23 pints of donated blood were used. I was told that donated blood was used because the heart-lung machine damaged the platelets.

9. When I had my heart operations in the 1970s and 80s these were long (approximately 14-hour operations). I was told at the time that there was a 20% survival rate. I remember being advised that the operations were high risk and discussions surrounding whether or not my body would withstand it. I do not recall ever being advised of the risk of a blood infection.

10. I have continued to experience symptoms as a result of my aortic stenosis throughout my life which has required regular medical treatment.

Discovery of Infection

11. In or around July 2016 I had what was supposed to be minor haemorrhoid surgery at GRO-B hospital, however unfortunately I suffered complications and was not discharged for 2 months. In September 2016 I had a severe pain in my shoulder and attended A&E at GRO-B hospital in relation to this. Initially doctors diagnosed me with a severe chest infection and I was prescribed an antibiotic. I also underwent a CT scan on the same day.

12. Following the CT scan, I received an appointment letter from the hospital. I assumed this was a review of the haemorrhoid operation I had in July 2016. Instead when I attended the hospital I discovered my appointment was with a hepatologist. He told me that unfortunately abnormalities in my liver had been detected on my CT scan. I was told that I had a liver tumour. I was referred to Kings College for treatment for the tumour as they had the facilities to treat both my liver tumour and my heart condition.

13. Unfortunately, in October 2016 I had a severe bout of arrhythmia which required me to be admitted to GRO-B hospital. This treatment took precedence over treatment of my tumour GRO-B was unable to solve the tachycardia and I was

transferred to the critical heart ward at Kings College Hospital. I was then transferred to the liver unit at Kings College Hospital and there was a lot of discussion amongst physicians about how my tumour could be treated. I understood that the usual treatment was to surgically remove it, but because of my heart condition this would be too risky in my case. I felt extremely depressed at this point. I decided I was going to give up and discharge myself. My wife talked me around to staying and have the liver treatment.

14. It was decided to treat my tumour with TACE which is a non-surgical procedure where chemotherapy medication is injected directly into the tumour. The arteries around the liver are then blocked to make sure the medication does not escape. In order to undergo TACE treatment I have to stop my anticoagulants (which I take for my heart condition) for a week before hand.

15. I had my first TACE treatment in December 2016 I had regular follow ups after each TACE procedure to ascertain the effectiveness of the treatment. In May 2017 in connection with follow up to my TACE procedures, I went for a further CT scan and saw the consultant in the afternoon. In passing the consultant told me that my blood tests showed I have Hepatitis C which is what caused the liver tumour. I am sure they must have known I had Hepatitis C before I was told. I feel I should have been provided with this information as soon as my physicians became aware of it.

16. The Consultant said quite casually "I suppose we ought to do something about that". On this occasion I was not given any further information about the Hepatitis C infection. It was left to me to look up on the internet to understand more about Hep C and how to manage it. I thought the manner in which the news was delivered to me was very strange and may cause distress to others. I consider myself fairly robust as a result of my previous medical history however, and so I did not find the manner of delivery too upsetting. In fact I was relieved that a cause for the cancer had been diagnosed.

17. I was referred to my local hospital at GRO-B for treatment for Hepatitis C in June 2017. Mr GRO-B who is the Liver Consultant at GRO-B Hospital suggested I most likely was infected during one of my heart operations, in fact he was convinced of it. This made sense to me as I had been virtually teetotal since my heart condition was diagnosed in the 1970s, so I knew the cause could not be an over indulgence of alcohol. I have also never taken intravenous drugs, had a

tattoo or body piercing or come into contact with anyone who has been infected with Hepatitis C to my knowledge.

18. I have never been given any information about the risks of infecting others. I was aware that the infection could be transmitted to others and so got my wife to have a test. This was not suggested to me by anyone. I am also aware that I should tell people taking blood from me that I have Hep C, this is not something which was suggested to me by anybody.

Section 3: Other Infections

19. After one TACE procedure in summer 2017 I collapsed on the train home feeling very ill and shaking violently. I went back to A&E and was diagnosed with sepsis as a result of contracting an infection from the catheter insertion. This was a life threatening secondary infection which would not have happened if I was not been treated for liver cancer which I developed as a result of my HCV infection.

Section 4: Consent

20. I do not believe I have been treated or tested without my knowledge or consent or without being given adequate information or for the purposes of research.

Section 5: Impact

21. Before I discovered I had a liver tumour, I was used to living with my heart condition. However, I found the combined effect of learning I have a heart problem and liver cancer had a major psychological effect on me. It almost sent me over the edge, it was too much to bear.

22. The physical effect of being infected with HCV has also taken its toll. I was treated at GRO-B hospital, I was told that there was a new treatment for Hepatitis C with a 98% chance of a complete cure. The treatment was in the form of a three month supply of tablets. The medication is extremely expensive and so in order to qualify for the treatment, you need to be assessed by a hospital committee as to whether you are eligible. I think that the information provided was sufficient given that the treatment had not been around long enough for physicians to get any detailed feedback. It so happens my sister in law is a retired

pharmacologist so she told me about the change in medication, I got more knowledge from a family member than from any hospital.

23. I then had to go to GRO-B hospital for a special scan and blood test to assess whether it was viable for me to be given the cure for the Hepatitis C. if they think you are too far gone they will not give it to you. The tumour was stage 1 I believe if it had been stage 2 or more they would not have authorised it. [The prospect of not qualifying for the Hep C treatment was very stressful, and my brother volunteered to pay for a private treatment in case my application was refused.

24. GRO-B hospital committee agreed they would give the medication in June 2017. I saw a nurse on a regular basis to obtain the medication for three months.

25. As above, as a result of being infected with Hepatitis C I have developed liver cancer. I have had four TACE therapies since June 2017. It takes me about two weeks to recover from each procedure. During this period, I am regularly physically sick with extreme pain in my abdomen. I also experience loss of appetite and find I cannot function well mentally. For example, if I am trying to work a calculation which on a normal day would take me half an hour can take me an awful lot longer. As a result, I tend not to work when I am recovering from TACE treatment.

26. There are also complications which can occur as a result of the treatment. For example, in February 2018 some of the chemotherapy medication leaked into my blood stream. I was severely ill for several weeks, with intense pain in the abdomen. I also lost my hair, and developed secondary severe throat infections. I was unable to get out of bed for a week as a result.

27. As a result of my liver tumour I experience ongoing low-level pain and discomfort in abdomen and groin on a daily basis and regular headaches. I have to have CT scans every three months which is a very unpleasant procedure. I have to have a cannula put in, which is painful. I am also allergic to the dye used which gives me severe migraine and bad rashes. This lasts for about 6 weeks after the procedure.

28. In terms of the impact being infected with Hepatitis Chas on my dental care, as above I have developed liver cancer as a result of my HCV status and am undergoing TACE treatment as a result. My dentist will not treat me when I am

undergoing this treatment. For example I have cavities in my gums which need flushing and have not been able to access this treatment.

29. Being diagnosed with liver cancer and not being able to access a complete cure has had a detrimental effect on my family. They constantly worry about me, they also find it difficult to visit me as hospital is 2 and a half hours away.

30. My liver tumour has also had a detrimental effect on my professional life and finances. In summer 2016 I was running a very successful salary sacrifice business distributing insurance through schools, universities and companies. The turnover was approximately £250,000, this has subsequently gone down to £40,000 in the last accounting period as I am unable to work as often and to the same level as I could previously. I would estimate my work input is only around 20% of what it was prior to TACE treatment

31. Before my cancer diagnosis I was also involved in building of an affordable property trust. I personally invested £250,000 into the business and I was involved in the raising of funds for affordable housing to replace government grants for housing associations from occupational pension schemes. This was potentially a multimillion pound business. Unfortunately, I had to step back from the business as a result of my liver cancer. As a result, the business has not made any profits and is struggling to get off the ground. I have lost the money I invested in the business.

32. My wife also has a financial background and has had to take over the running of our pensions claims handling business, with me not being as involved in it as previously. This is difficult for her as she had retrained in 2008 as a psychotherapist, gaining a masters degree in order to give something back to society. She does not have as much time to do this as she hoped as a result of my illness and had to relinquish her job working for the NHS as a CBT specialist.

Financial Assistance

33. I have received a lump sum payment from the Skipton Fund as a result of my HCV status. I got £70,000 in two payments in summer 2017. I also receive a monthly payment of £1,500.

34. I found the Skipton Fund myself on the internet. Nobody treating me signposted me to this. I found the application to the Skipton Fund relatively straight forward given my experience in making complex pension claims.

35. I had to supply the Fund with medical records and have several forms filled out and signed off by senior clinicians at Kings College Hospital.

36. However, I would comment that I recently received information (in error) from the NHS body which have taken over the Skipton Fund about initiating a claim. I found their methodology of making a claim virtually impossible and the information provided most unhelpful.

37. I don't believe the value of the compensation offered by the Skipton Fund is adequate. It is very difficult to put a price on what I have experienced and the impact on my life as a result of being infected with HCV.

Statement of Truth

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

Signed: .... GRO-B

Dated: 04/12/2018