Witness Name GRO-B
Statement No: WITN1339001
Exhibits: WITN1339002
Dated: October 2018

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 GRO-B and I live at GRO-B GRO-B with my wife. I have a grown up daughter.

2. I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 15 October 2018.

3. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Infected

4. I was diagnosed as having severe haemophilia A by Dr Morris, a paediatrician at my local hospital in GRO-B in or about 1955 when I started bleeding heavily from my gums after having several teeth removed.

5. I was infused with stored blood which had no Factor VIII in it (because Factor VIII has a half life of 12 hours) and when the bleeding didn't stop I was transferred to Lancaster and infused with fresh blood.

6. At that time there was no treatment for haemophilia. At one stage I was treated with snake venom to try to clot my blood when I had teeth out.

7. Throughout my childhood I suffered from joint bleeds which have resulted in arthritic changes in most of my joints in later life.

8. Between 1955 and 1976 I was treated at the Manchester Royal Infirmary. In 1969 I was told that cryoprecipitate would be available to GRO-B Hospital in GRO-B shortly and I would be able to receive treatment nearer to home. In 1969/1970 I was treated in GRO-B with cryoprecipitate.

9. In 1974 there was a change in the local health authority boundary due to a re-drawing of county boundaries. I had heard from another haemophiliac that comprehensive haemophilia care (ie. covering all aspects including dental, physiotherapy etc) was provided by the Haemophilia Centre, Royal Victoria Infirmary, Queen Victoria Road, Newcastle Upon Tyne, NE1 4LP and I therefore asked for my treatment to be transferred there. I started attending Newcastle in 1975. I was one of three haemophiliacs in GRO-B who transferred to Newcastle.

10. My consultant at the centre was Dr GRO-D and it is here that I was infected with Hepatitis C as a result of being treated with infected blood products.

11. I was treated with numerous blood products as listed in my medical summary below, including Koate, Factorate, Profilate and Hemofil. I have now also received a copy of my records from the National Haemophilia Database. These are attached to my statement as **[WITN1339002]**. These records refer to Dr Craske's research work. I was not aware of any involvement with Dr Craske or any of my blood samples being referred to him.

12. In 1976 I was the first of the three GRO-B haemophiliacs to go onto home treatment with concentrate, so I could administer these products at home instead of requiring hospital treatment. This involved administering several treatments of Factor VIII a week. Dr GRO-D informed me that I was the GRO-B person in the UK to be doing this.

13. I was on prophylaxis treatment for a period of time. Over the years I have had both knees replaced with prosthetic joints, surgery on my left elbow and fusion of both ankles. As I have had less frequent bleeds I have reverted to on demand treatment.

14. I currently administer on demand treatment at home 3 – 6 times a month.

15. I was never given any advice or warnings as to the risks associated with blood products or whether they were safe to administer.

16. The first time I became aware of any risk was when I watched the programme 'World In Action' in 1975, which highlighted the potential risk due to the sourcing of blood from vagrants. However this was never discussed with me or raised by my doctors.

17. I believe that I was first told about my diagnosis of Hepatitis C by Dr GRO-D GRO-D in or about 1993 or 1994. I cannot recall when I was made aware of my diagnosis but I believe it was around this time and I note from the entries in my medical records that there are references to discussions about Hepatitis C in 1993 and 1994. Prior to this I may have been aware that there was a non A, non B virus being discussed amongst haemophiliacs.

18. Dr GRO-D told me that it was nothing really to worry about and he did not expect it to be troublesome. I had known him for such a long time at that stage that I considered him a friend and I was reassured by his comments. I also remember thinking that I was more likely to die in a road traffic accident on the way to the treatment centre than I was to die from Hepatitis C because I had to travel a 300 mile round trip to the Centre. I do not recall if Dr GRO-D informed me of possible routes of transmission, however I already had an understanding that viruses could spread through blood and sexual intercourse having researched HIV.

19. I recall being told that I had tested negative for HIV but remaining worried about the potential for infection for a number of years afterwards because I had read that you could initially test negative for the virus but later test positive because the first tests for HIV were not very sensitive. In 1985/6 I did a lot of reading about HIV and one night I was so concerned and fixated on the problem that I telephoned an advice centre in San Francisco.

20. Having been diagnosed Hepatitis C Genotype 4, it is my belief that I was likely contaminated by blood from Africa as this type of Hepatitis is predominantly found in the Middle East and Africa.

21. I remember feeling that there was a palpable sense of shock at the Newcastle Centre regarding the level of illness amongst the haemophiliacs being treated there. I do not know whether Dr GRO-D and the nurse involved, Sister Maureen Fearns, had been made aware that there was an issue or whether it was just shock at the level of illness suddenly upon them. Dr GRO-D was taken off the job and moved away from treating patients in the clinic. His work was taken over by Peter Hamilton, a haematologist.

22. Dr GRO-D was a strong advocate for the use of factor instead of cryoprecipitate because his view was cryoprecipitate was not as effective. It was certainly life changing for me to be treated with concentrate because it gave me the freedom to do things that I could not have done if I had been continued to be treated with cryoprecipitate because of the volume of cryoprecipitate that had to be administered to achieve the same effect as concentrate. Infusion with

cryoprecipitate required attendance at the local hospital and after defrosting it was infused by drip. In contrast, concentrate was maybe 20 mls in volume and given by syringe intravenously. With concentrate I was able to treat myself at home as soon as I felt a bleed starting which meant the bleeding was stopped at a much lower level. The speed with which the coagulant level was raised is important because the hours that cryoprecipitate took to take effect went from minor to major. This hastened joint damage because of the length of time blood was on the joint.

23. That said, I do not recall anyone discussing the risks and/or benefits of the alternative treatment options with me and I was certainly never told of the risk of infection from blood products.

24. As set out above I have also now seen reference to Dr Craske's research in my records from the National Haemophilia Database. I was not aware that my records and/or samples were being considered by Dr Craske.

25. In or about the early 2000s I had a friend who was a director of a pharmaceutical company who told me that the CEO of his company had been approached to take over the Blood Products Laboratory in Elstree. My friend told me that the CEO had been told not to touch it with a barge pole because the Laboratory was unhygienic and in a terrible state. It was also rumoured that some of the blood companies were providing credit cards for the blood collection centre heads which could be used for anything and were then paid off in full by the blood companies.

Section 3. Other Infections

26. In or about 2001 I received a letter from Dr Peter Hamilton, haematologist, advising me that I might have been exposed to non variant CJD. I was told that there were no tests available and asked whether I wanted to know about it. I decided that I did and went to see Dr Hamilton. He told me that I had been exposed. I was then left thinking that I had been exposed to 3 life

threatening conditions although to date I have only been diagnosed with one of them.

27. Dr Hamilton told that there was some research taking place in Scotland in relation to CJD and I said that I was happy to have blood taken for this. I do not know what happened to those samples and whether they have been shared.

Section 4. Consent

28. I do not recall being asked about testing for Hepatitis C. Blood was taken from me frequently (every time I attended clinic) however I was never told what they were doing with this.

29. I believe I was tested for HIV in or about 1984 which was when the haemophilia community first started getting worried about HIV/AIDS. I do not remember testing being discussed with me beforehand. I only recall getting the results of the test.

Section 5. Impact

30. My infection with Hepatitis C has seriously affected my personal and family life. I am extremely cautious as to the risk of infecting those around me. This is the main reason that I have been celibate since shortly after my diagnosis, which has severely impacted on my relationship with my wife. Even though we used condoms previously I was not prepared to take any risk at all with my wife's health. I have missed that side of our relationship and dealt with it by masturbating when necessary. However, this makes me feel like some teenage boy rather than a grown man in a long term, committed relationship.

31. Whenever I have an accident that involves any blood show I always had to be proactive and practice good hygiene. I made sure that the blood was cleaned and the area thoroughly disinfected to manage to risk of infection.

32. Being infected with Hepatitis C changed me psychologically as well as physically. I adopted a 'glass half empty' attitude to life, and I became very susceptible to anger. I was often an unpleasant person to be around when I was suffering from the infection and whilst receiving the Hepatitis C treatments, and it is to my wife's credit that we are still together.

33. I was also fatigued a lot of the time. I noticed that I tired easily and would have to nap after only limited physical exertion.

34. My friend GRO-B: F and my nephew GRO-B: N were both co-infected with Hepatitis C and HIV. When N was 20 years old (in or about 1992), he had applied for a place at GRO-B As I had previously taken some classes there, I offered to take him to GRO-B to visit the university one Saturday but the Monday before I learnt he had fallen seriously ill, by the Tuesday, when I went to visit him in hospital, he had fallen into a coma. He was transferred to Blackpool on the Friday and died there on the Saturday. My friend F passed away a few years after.

35. At that time I had medically retired, my wife was working and I was at home without a clear role. I experienced survivor's guilt after their passing and suffered from depression. I struggled to come to terms with why I had survived and they had both passed away, especially N who was so young.

36. I was offered counselling sessions with a mental health nurse in 1994. These sessions would be every few weeks over the course of 6 months, and ended in February 1995. These sessions gave me the opportunity to cry and express my outrage at everything that happened and I do believe they helped me; however I do still suffer from a sense of guilt to this day.

37. I was also extremely anxious and worried about my chances of being infected with HIV. I remember the sense of shock at the Royal Victoria Infirmary at the level of the illness amongst the infected, which only increased my fear. I once called a HIV advice centre in San Francisco when I felt I had no one else to turn to. This was a big step for me at the time.

38. I have suffered from the stigma of being diagnosed with Hepatitis C and being linked to HIV. When I had two polyps removed following a bowel scan I was told that the probes would have to be isolated until they could be cleaned because I was Hepatitis C positive.

39. My dental work always has to be carried out at the centre in GRO-B and my treating dentist always wears glasses and a visa helmet as a precaution when treating me.

40. When I was in hospital for surgery on my elbow, I was put in a side ward on my own. The nurse told me I would not be allowed to use the hospital toilets, and would instead have to use a commode or a bedpan. After I kicked up a fuss, I was told I could use a toilet that had been made available only for me. It was only after leaving the hospital that I discovered my notes that were sent to the hospital stated that I was Hepatitis C and HIV positive. I believe this is why I was made to feel so uncomfortable and treated like a leper by the staff. The HIV positive result had in fact been corrected as it was an error in my records.

41. The stigma has also affected my family life. After the birth of my grandchildren, my daughter expressed her concern that her children might become infected via the toilet seat. I now only sit on the toilet pan wherever I go to eliminate the risk of infecting others. I also therefore avoid going to the toilet in public bathrooms. This makes me feel very uncomfortable.

42. Despite the stigma attached, I have never hidden the fact that I suffered from Hepatitis C, however I have been cautious of publicising this too much.

43. I feel that my illness has impacted on my personality over the years. The strain of the HIV testing, the diagnosis of Hepatitis C and deterioration of my liver followed by two courses of treatment took its toll and meant that I became easily stirred to anger. This change has also impacted on my marriage. I became very obstinate and not very nice to live with. It is a great credit to my wife that she has continued to support me and stage with me. I do not think that I was always the father I might otherwise have been – I tried

but would often by overcome by rage. I now wonder if I suffered a form of PTSD producing these mood swings.

44. As time has gone on I have become more introspective and with growing self awareness have been able to curb those tendencies but that has taken a long time. I feel that Hepatitis C has changed me as a person – I feel physically and mentally damaged by it.

Section 6. Treatment/Care/Support

45. In 2001 I received 48 weeks of treatment with Interferon and Ribavirin in an attempt to clear the virus. The side effects I suffered were horrible when I received these treatments. I had an eczema-like reaction which meant that my skin was always itchy. Some nights I would be unable to sleep as I could not stop scratching. The only thing given to relieve these side effects was a product to put in my bath water. My serotonin levels were also reduced, which severely affected my emotional levels. The slightest triggers would make me weep, and I had little control over my emotions. I also experienced a lot of fatigue during this period.

46. It was initially believed that this treatment had cleared the virus, but this was not the case. In 2012 I received further treatment with Interferon and Ribavirin, however this treatment was stopped after 26 weeks as it was considered to be having no positive affect. This time I would occasionally suffer from some of the side effects that I suffered with before. I also suffered from extreme itching around my anus which would often bleed. This was extremely uncomfortable, and the cream I was provided with to help this only made it slightly more bearable. These are the side effects that I remember most. There were also other, less unpleasant side effects.

47. It was only when I became active on the internet that I became aware of the treatments available for Hepatitis C and when new treatments were available (in particular Harvoni). I approached my treating hepatologist and asked about the treatment. Initially I was told that my liver function tests were not

urgent enough. At the time the treatment was being limited because of cost and a case had to be made to NHS England. My doctor subsequently re-applied and managed to secure funding. I feel that my treating hepatologist and haemophilia consultant over the last 10 years have done their best for me.

48. In November 2015 I started treatment with Harvoni and Ribavirin. This treatment was effective and I had cleared the virus by January 2016.

49. By April 2016, this treatment became available to everyone with Hepatitis C after national pressure was applied and was not limited to those with just advanced liver failure.

Section 7. Financial Assistance

50. I received a stage 1 payment from the Skipton Fund of £20,000. By 2016 my liver had become cirrhotic and deteriorated to such an extent that the trigger point for Stage 2 had been reached. I received my stage 2 payment of £50,000 in June 2016 and, in addition, the monthly payment which is triggered by Stage 2. By the time you meet the criteria for the Stage 2 payment you are not expected to live much longer.

Section 8. Other Issues

51. In 2002 I joined with others in a class action in the US.

52. I instructed Lieff, Cabraser, Heimann and Bernstein LLP who initially acted on behalf of UK clients only and an offer was made in a Californian court of a six figure sum on the test cases who were dual infected. They decided then to take on clients from around the world and the court cases were switched to Chicago. The UK cases were rejected there and were to be heard in the UK. We had reached an impasse because we were told that under UK law we needed to prove a specific date of infection which was impossible. A

settlement was made which resulted in me receiving a payment of just over £5,000.

Anonymity

53. I confirm that I wish to apply for anonymity.

Statement of Truth

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

Signed......... GRO-B ....

Dated......... 31-10-18 ....

MEDICAL SUMMARY

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)

Blood Products Used (prior to diagnosis)

15.12.1977 - 20.12.1977	Hemofil X
25.03.1978 - 23.09.1978	Koate / Koate 03 Hemofil / Hemofil 08
31.05.1979 - 09.11.1979	Factorate / Factorate 09 Koate / Koate 03
05.05.1980 - 18.12.1980	Koate / Koate 03 Factorate / Factorate 09 Hemofil / Hemofil 08 Profilate / Profilate 02
09.04.1981 24.08.1981	Koate / Koate 03 Humanate / Humanate 10 Factorate / Factorate 09 NHS Hemofil / Hemofil 08 Profilate / Profilate 02
16.03.1982 - 25.08.1982	Factorate / Factorate 09 Koate / Koate 03
20.01.1983-16.06.1983	Koate / Koate 03 Factorate / Factorate 09 Hemofil / Hemofil 08
19.8.1984-19.12.1984	Koate / Koate 03

15.06.1985-26.11.1985	Koate / Koate 03
29.1.1986 – 25.7.1986	Koate Profilate
17.12.1987 -21.12.1987	Profilate
02.06.1988 -31.12.1988	NHS Profilate
03.01.1989 - 22.12.1989	NHS
24.03.1990 – 24.12.1990	NHS Profilate M58YX4 / M/S8Y
01.03.1992 – 28.02.1993	Profilate
01.01.1993 – 31.12.1993	Profilate NHS VIII
01.01.1994 – 15.09.1994	8Y Profilate Monoclate P

Clinical Biochemistry

04.12.1990	HIV antibody negative. Hepatitis C. Evaluation of the current test has shown it to be unreliable. There is at present no test for acute infection or a confirmatory test and the service for Hepatitis C is therefore not available. Please discuss with Dr A A Codd if necessary.
28.03.1991	Evidence of previous exposure to Hepatitis B. Further Hepatitis B testing NOT indicated. Vaccination NOT indicated.

HIV antibody –ve

15.12.1992 Hepatitis C antibody positive by ELISA. RIBA: 4 bands.

08.09.1993 Haem A

26.01.1994 Hep C +ve

15.09.1994 Haem A. HIV POS

10.02.1995 Haem A; HCV +; HIV -

<u>Other Entries</u>

03.06.1975 Letter from the Royal Victoria. Patient to be treated there following shift in the Regional Health Authority. He is a severely affected haemophiliac and his factor VIII is less than 1%. He does not have an antibody against factor VIII. In the past his major bleeds have involved the knees, both ankles, the left elbow and the muscles of the right forearm and both wrists. He has also had haematuria following a blow to the left kidney region, the occasional epistaxis and what sounds like a Mallory Weiss episode earlier this year. The major problem has been his left knee……He receives intermittent Cryoprecipitate therapy on demand in GRO-B …He has had a good deal of sick leave in the past year and his chief worry concerns promotion in the Civil Service. The GRO-B have one daughter, who will be an obligatory carrier, and they have decided that they definitely do not want further children….While in GRO-B M GRO-B had a long talk with Mr Morgan our social worker about his employment worries. With the distances involved and the frequency of this man's bleeds he would obviously benefit from home therapy with factor VIII concentrate………we will arrange his admission to the RVI in early July for surgery and home therapy training.

1976 Home treatment.

24.04.1979 Letter from The Royal Victoria. In the past year he has used rather more than the average amount of facto VIII and in view of this and the continued haemorrhage into both knees I have started him on prophylaxis. He will now give himself one vial of factor VIII on every third day, and continue to treat his bleeding episodes……Blood count normal; liver function tests show a slight raise in S.G.O.T.

25.03.1985 Letter from GRO-D to GP. Patient being kept on prophylaxis. He has been under some stress at work, and is obviously worried about AIDS but has managed to come off Diazepam. I was able to reassure him that firstly there were no abnormal findings relating to the disease and secondly that both he and his wife are HTLV III antibody negative.

30.04.1985 Letter from GRO-D to GRO-B *"I am writing to you as one of the very few people to be HTLV III antibody negative in our Region. There is some debate, principally amongst people not concerned with the clinical care of haemophilia, about whether it would be better for you to stay on heat treated factor VIII or be switched to volunteer donor cryoprecipitate which has been prepared from plasma from HTLV III antibody negative donors in our Region. Rather than influencing you by telling you my opinion now, I would be grateful for any thoughts you have on the matter."*

10.04.1986 Letter from GRO-D to GP. Patient has come off prophylaxis. He remains anti HTLV III negative.

01.04.1987 Letter from GRO-D to GP. He is presently HIV antibody negative and the results of tests sent recently to London for antigen tests have also proved negative.

22.02.1988 Letter from GRO-D to GP. He remains HIV antibody negative. He remains on his Alpha heat treated Profilate.

24.10.1990	Letter from the patient querying information he say in the papers regarding an AIDS conference in San Franscisco.
09.11.1990	Letter from GRO-D to patient confirming the information from San Francisco was muddled and that tests had become more sensitive so more people who were infected have been picked up. In the early days some people who were HIV negative were later found to be infected but doubt there more than a handful who would fall into that category today.
10.12.1990	Letter from haematologist (Dr Peter Hamilton). *"He needs reassurance that he is one of the lucky ones that does not have HIV. I reassured him that even in patients who have had a lot of concentrate molecular biological investigation still reveals them to be negative if they test negative for the other tests. I think this was a great relief to him."*
15.04.1991	Letter from GRO-D to GP. Back on prophylaxis of 20 units of factor VIII every third day.
Oct 1991	Fell badly, R knee damaged. V painful on minimal walking. Prophylactic FVIII 250 alt days.
22.11.1991	Letter from GRO-D to GP. Remains on prophylaxis on alternate days. Blood count and liver function tests normal and he remains HIV antibody negative.
28.06.1992	Letter from Patient to GRO-D Patient on sick leave whilst employed by GRO-B and considering medical retirement option that staff welfare had urged him to consider.
12.11.1992	Routine admission for R arthroplasty.
13.11.1992	Note made by GRO-D in relation to the admission for replacement of the right knee. Anti HBs and HBc positive.

15.12.1992 Admitted for pain and swelling in R knee. Thought he was having a bleed. Noted HIV/Hep B –ve.

16.03.1993 Letter from GRO-D to GP. He has an antibody to hepatitis C and I discussed this with him. Thankfully his liver function tests have not been markedly abnormal so he is not presently a candidate for thinking about treatment with Alpha Interferon.

20.01.1994 Haemophilia centre follow up. Discussed hepatitis C.

26.01.1994 Letter from GRO-D to GP. He is reluctantly continuing his prophylaxis. He has had a few bleeds over the last year and all have stopped with one treatment. I am sure if he stopped the prophylaxis he would have multiple bleeds. He doesn't like injecting himself. He is still suffering the occasional bout of depression and panic attacks. He has never been suicidal. Recommended counselling. We also discussed his hepatitis C infection. His LFTs have not been markedly abnormal. If recent result is raised will arrange a liver scan next time.

03.07.1994 Letter from GRO-D to Patient. One of LFTs was somewhat higher than normal and I therefore think we should arrange a liver scan, but there is no hurry.

10.06.1994 GRO-D wrote to Patient with results of liver scan.

22.06.1994 Summary of counselling assessment/review. He described 1984-5 as a particularly stressful time when the HIV scare was very prominent, he was tested HIV negative but has over the year lost a lot of acquaintances with AIDS related illnesses and finds himself experiencing feelings of guilt.

27.09.1994 Letter from GRO-D to GP. Patient still unhappy with his prohylaxis. Liver scan was normal. Latest ALT slightly raised at 67 u/l (normal range 5-43 u/l). Have asked Peter Hamilton to advise whether to do a baseline liver biopsy.

06.02.1995 Letter from GRO-B Community Mental Health Centre. *"I have been seeing GRO-B over the last six months, offering counselling…GRO-B feels that counselling has enabled him to become more self aware. He is slowly coming to terms with the changes that have taken place in his life. He is more positive regarding the future….I have now discharged him from my caseload."*

15.02.1995 Liver scan in September 1994 was normal and his LFTs were only slightly abnormal, a finding echoed on the present testing in which his ALT was 50 u/l. Case discussed with Dr Hamilton who felt, given the normal scan and the present liver function tests, a biopsy was not indicated.

29.09.1995 Confirmed immunity to Hep A following course of vaccinations.

08.04.1997 Letter from GRO-D to GP. Patient had attended a residential weekend for patients and their families. He has become lazy and attributes his eating to boredom. Another discussion re Hep C and he would prefer to wait rather than consider interferon therapy at this stage. He is also suffering from headaches.

10.04.1997 Letter from Patient to Dr GRO-D confirming he wants to do trial.

14.05.1997 Letter from GRO-D to patient. Reluctant to encourage patients who are unsure and are prone to depression onto the trial.

07.10.1997 Letter from Peter Hamilton to GP. On balance he does not need treatment with interferon and Ribavirin for Hep C at the moment.

21.02.2000 Haem A/Hep C Inhibitor screen negative.

09.11.2000	Letter from Peter Hamilton to GP. He would like another viral load check in 6 months when we may consider liver biopsy to see whether he should embark upon treatment. By then we will know if he needs a year or 6 months with Interferon and Ribavirin.
14.06.2002	Letter from Peter Hamilton to GP. GRO-B is very introspective and through using the internet knows a lot about Hep C and the complications of treatment.
27.09.2001	Leter from Peter Hamilton to Benefits Agency. He suffers from debilitating symptoms of Hep C and cannot carry out employment.