Witness Name: GRO-B
Statement No:WITN1531001
Exhibits:0
Dated: December 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 My date of birth is GRO-B. I live with my wife and son at GRO-B. I currently work as a GRO-B.

2. 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

3. I have mild Von Willebrand's disease type 1. I was diagnosed in GRO-B at the GRO-B in GRO-B, when I had teeth extracted, which caused significant bleeding to my gums. There is a letter in my notes dated 10.12.1981 (dictated date) which states that I was "diagnosed as having Von Willebrand's disease in GRO-B, following prolonged bleeding after dental extraction". The date that I was diagnosed in the letter is incorrect. I had my

teeth extracted in GRO-B and after taking blood tests because of the bleeding, I got the results back in GRO-B and that is when I was diagnosed with mild Von Willebrand's disease.

4. At the time my condition was very rare, however, it runs in my family, as my GRO-B had the same condition. My GRO-B:F was tested for Von Willebrand's disease in his GRO-B, not long after my diagnosis and it was confirmed that he has the same condition as myself. My F has now passed away.

5. After I was diagnosed, I was transferred to The London Hospital (Whitechapel Hospital) (now called The Royal London Hospital). This is where all the haemophilia patients were being transferred to, as they specialised in Von Willebrand's disease. Once I became their patient I was given a little bit more information about my condition, including practical information, such as not to take aspirin, or other blood thinning drugs.

6. In September 1981 when I was approximately GRO-B and I had, what was termed as slipped right femoral epiphysis, the hip was pinned under a general anaesthetic and I was given 15 bags of Cryoprecipitate. After my operation I was given a further 5 bags of Cryoprecipitate at six hourly intervals, with intravenous Tranexamic Acid 500mg. The following day the Cryoprecipitate was reduced to 8 bags, 12 hourly. I developed sepsis and became unwell and I was not given anymore treatment that day.

7. By the GRO-B I was mobile but non-weightbearing and prophylactic pinning of the other epiphysis was arranged for the GRO-B. The same treatment of Cryoprecipitate and Tranexamic Acid was followed. On the night following the second operation I developed a reaction to Cryoprecipitate. The doctors therefore had to terminate it. As a result of this my first dose of Factor 8 (FVIII) concentrate was administered the following morning. I was then given 12 micrograms of DDAVP on the evening of GRO-B and again the following morning. By this stage I was pain free and I did not require factor FVIII or DDAVP. I was mobilised on crutches and continued on oral

Tranexamic Acid until I was discharged on the GRO-B. I had the pins removed approximately 3 years later and I was given DDAVP.

8. Considering that my Von Willebrand's disease is mild, this was the only time when I had FVIII products administered, and I do not believe I should have had it. This is because on all other instances, where I had bleeds, or needed treatment I was given DDAVP, which is synthetic and does not pose any risk of serious infections. I was given DDAVP from the date I was diagnosed, for example for my dislocated ankle and other teeth extractions.

9. My F never had infected blood products administered, only DDAVP for the exact same condition; therefore I believe that my condition could have also been managed solely by the synthetic alternative.

10. When I had the operation to my GRO-B, I believe that the team at the Oxford's Haemophilia Centre knew that something was not right. I know this now because of a letter, dated GRO-B (from GRO-B, Senior Lecturer in Haematology) stating that my enzymes were slightly raised and that I must have developed non A non B hepatitis. They had not come across Hepatitis C by this point yet, so I believe that they could not have tested me for that yet.

11. What caught my attention from the above letter (GRO-B, was that he 'does not want to worry the patient', in relation to the test results, and that they are to 'keep an eye on me'. My parents were not informed of this letter. Instead, my parents received a different letter from GRO-B, which was dated the same as the letter to my GP, stating that there were 'minor changes in my blood test'. There was no mention about me developing non A and non B hepatitis in the letter to my parents.

12. I went back to the hospital in or about 1983 for an outpatient appointment, where I thought I was having routine blood tests for my condition. At no point was I told what the blood tests were for. I was called back 3 weeks later to have further blood tests, again I was not told what the blood tests were for. It

is now obvious to me that they must have found something at the time as per GRO-B letter above and they wanted to keep an eye on me.

13. I had regular routine check-ups (every 6 months / every year) at the time, which my parents and I assumed was for my condition. At no time were we told what the blood tests were for.

14. I always had regular dental check-ups. In GRO-B it became apparent that I needed to have both of my lower wisdom teeth removed.

15. On GRO-B I went to see GRO-B at The Haemophilia Centre, London and I thought it was going to be a review meeting about my wisdom teeth extractions. However, this was when I was informed that my test results for HIV, Hepatitis A and B (Hep A & B) were negative and I was Hepatitis C (Hep C) positive. I was shocked, as I had never suspected that I could have been infected with anything. I was even more shocked, because I thought I was only attended the hospital for my dental review. I was not prepared for this. In GRO-B letter to me, dated GRO-B he states that I knew that I had mild liver inflammation back in 1981 and he was sure that was the cause of the positive result. This is not correct, my parents and I were never informed that I had mild liver inflammation back in 1981 and there was a possibility that I might have the infection.

16. I strongly believe that if I did not go to the The Haemophilia Centre, London in September 1994 and had the 'routine' blood tests done, the doctors would not have told me that I was Hep C positive.

17. When I had wisdom teeth extracted in or about 1994/1995 I was given DDAVP and no other blood products.

18. After I found out that I was Hep C positive I contacted GRO-B, in order to seek more information. I saw GRO-B in September 1994 and he explained the basics of Hepatitis C virus (HCV); the fact that I must have been infected with Hep C through the infected blood products, which were given to me when I had prophylactic pinning of the other epiphysis in October 1981. I was told that there was a low risk in sexually transmitting the virus and the virus could

be dormant, but it could be re-activated in the future even though this seems unlikely. GRO-B also explained the need for regular follow-ups and warned me against alcohol abuse. I note from GRO-B letter that he states that he provided me with a HCV booklet. I do not recall receiving a booklet at that time.

19. I had regular 6 months check-ups for Hep C, all which were negative. I also had a liver function test, which was proven to be fine.

20. I then received a letter in or about March 1995 attaching a information sheet about Hep C. I found it problematic, as I have found out about being infected with Hep C back in September a year before, and I have not been given comprehensive information at the time. I strongly believe that the information about Hep C should have been provided earlier. I believe that perhaps I was provided with the information only because they have received a lot of telephone calls from people who were infected with blood products.

21. I am not sure if the information that I was provided about Hep C was adequate at the time, as I am not sure how much information the doctors had. I found some of the information quite scary, such as the fact that it might re-activate itself in the future.

22. I confronted GRO-B about why I was not informed about Hep C earlier and if I did not have the blood tests done prior to my wisdom teeth extractions, would he have told me that I was Hep C positive. I received an unsatisfactory response, GRO-B said that it would not be realistic to expect him to review all the patients' records that have been treated with FVIII and infected as a result.

23. I found it rather strange, as I would have assumed that the doctors knew their patients quite well. I must admit that I was quite angry with his response and the fact that I had to find out that I was Hep C positive on my own, rather than being told about it by the doctors earlier whilst I was having blood tests. I also found it rather scary, that there may have been people in the same situation as me who had not cleared the virus naturally and had to deal with the

infection. I believe that we should have been informed about it when the doctors were aware so that we had the chance to do something about it.

24. I now have routine check-ups once a year at The Royal London Hospital. I believe this is done so that the doctors can fulfil their duty of care.

Section 3. Other Infections

25. I did receive a letter on the 20 September 2004 attached with an information sheet about the different categories of vCJD. There are two categories of implicated batch, involving plasma donated by a person who later developed vCJD. I did receive a Category 2 plasma derived clotting factor prepared from United Kingdom donors between 1980 and 2001 but not from one of the implicated batches.

Section 4. Consent

26. Prior to my wisdom teeth being extracted I was never informed about any tests that were done for Hep A, B, C and HIV and nor were my parents. Nonetheless, it is clear that previous blood tests did take place and this is clearly confirmed in the letter from GRO-B, dated GRO-B, which stated that I was non Hep A and non Hep B.

27. I was a minor for a lot of the time when I was in hospital and it would have been for my parents to give consent to any blood tests that were done. It was not a custom at the time to question the doctors as to what treatment I was given or what blood tests they were doing, therefore all my parents did was take me to the hospital to have any check-ups that were necessary.

28. I believe the only information that might have been given to my parents regarding FVIII was that it was in the course of my treatment, but I am certain that they were not given any other information, as to the potential risks of infected blood products.

29. I believe that it is very possible that tests were carried out for research purposes. The London Hospital (Whitechapel) (now called The Royal London Hospital) worked closely with the Oxford Haemophilia Centre, and by looking at the correspondence between the doctors, I am sure that there must have been some tests done previously on untreated patients, as to what effects FVIII has.

Section 5. Impact of the Infection

30. As the Hep C cleared spontaneously, I did not require any treatment.

31. I did not have any obvious physical or mental effects of the Hep C itself, when I was infected. There was a period of time after I was given FVIII that I suffered from a persistent fatigue. However, I cannot be certain whether it was because of Hep C or other reasons.

32. The main affects I have now is that I remain anxious, as to the possibility of the Hep C reactivating in the future.

33. There is also the inconvenience of needing to have regular routine check-ups to ensure the Hep C has not re-activated.

34. My anxiety levels prove to be quite severe sometimes. I do think that it would have been better if I had never gone to have my wisdom teeth extracted and then I would have never known that I had Hep C and worried about it re-activating again.

35. Another negative affect of the infection is that only my wife and closest friends know about it. I always tried to keep it a secret due to the stigma attached to it. I never told my colleagues at work about it, as Hepatitis is associated with unsanitary methods such as tattooing or drug use and liver problems often associated with alcohol abuse. Of course, people are more educated now, but I still consider some stigma still remains.

36. I am married now and my wife is very understanding and supportive. However prior to my relationship I was very anxious of being rejected by people as a resulted of being infected with Hep C.

37. I am also worried that if the Hep C was to re-activate I would not be able to work. I have been in full time employment my entire life, and financial security is very important to me.

38. Lastly, I believe that the situation has had a negative impact on my trust towards the medical professions. I will always have what happened to me at the back of my mind. It had also affected my parents' trust towards the doctors, as I was under their care at the time I was infected.

Section 6. Treatment/care/support

39. After I found out that I was infected with Hep C, GRO-B advised me that I could see another doctor, in case I lost trust in him. However, I thought that since he knew practically everything about my situation, I would rather keep seeing him. I also thought that in case something was to happen to me, it probably be better to be treated by him as he knew my medical history.

40. I was previously offered counselling from the Haemophilia Society. However, I did not believe I needed it at the time. I was very close to my parents and they offered me all the support and comfort that I needed, especially when my F was also diagnosed with the Von Willebrand's disease. I also received support from my GRO-B who is a trained GRO-B and my wife was and still is, very supportive. I therefore believe counselling is not something that I needed. However, I can imagine that it must be very challenging for those people who do not have a similar support network.

Section 7. Financial Assistance

41. GRO-B informed me about the Skipton Fund, when it was first introduced. However, my application was rejected. The reason for this was, whilst I can prove that I was infected with the Hep C and the doctors also confirmed that I

was infected with Hep C as a result of FVIII, I cannot prove how long exactly the infection lasted, as there is no paper evidence as to any blood tests being done between the 1982 and 1985.

42. I did not proceed with the appeal, as the appeal requires very specific evidence, which I did not have.

43. The process in relation to applying for the Skipton Fund was straight forward. I filled out the application and then forwarded the application to GRO-B

Section 8. Other Issues

44. I believe that the enquiry should have taken place many years ago. It has taken too much time to reach this stage. Many people have been infected and many people have passed away as a result of being infected with infected blood products.

45. I consider myself lucky, as I have not infected other people.

Anonymity, disclosure and redaction

46. I confirm that I do wish to apply for anonymity.

Statement of Truth

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

Signed GRO-B ………………

Dated 6 DECEMBER 2018

Medical Summary

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

Virology Results

Undated	Australia (HB) Antigen - Negative
1982 – 1985	No blood tests results
13/09/1988	Anti HIV1 – negative Hep B Surface Antigen – Negative
21/09/1994	HCV Antibody reactive Hep A total antibody – Negative Hep B surface antibody – 0.0 – no antibody detected
02/11/1994	HCV antibody reactive Hep A total antibody – negative Hep B Surface antibody – no antibody detected
23/11/1994	HCV not detected
25/07/1995	Hep B Surface antibody – some protective antibody present. Booster dose of Hep B vaccine required and retest in 6 weeks

Significant Entries/Absent Entries

10/12/1981	Letter from GRO-B – Summary of case. An x-ray of the hip showed a grossly slipped right femoral epiphysis. Under general anaesthetic following the infusion of 15 bags of cryoprecipitate. Post-operatively patient given 5 bags of cryoprecipitate at six hourly intervals, with intravenous Tranexamic Acid 500mg, six hourly. The following day dose of cryoprecipitate was reduced to 8 packs 12 hourly. Subsequently he became unwell and the only obvious source of sepsis was phlebitis at the site of his intravenous cannula. This was, therefore, removed and not replaced and no further factor 8 cover was given. The same regime of cryoprecipitate and Tranexamic Acid was followed. On the night following the operation he developed a severe febrile reaction to cryoprecipitate which required hydrocortisone and piriton to terminate it. In view of this his first dose the following morning was administered in the form of NHS factor 8 concentrate 500 units. He was subsequently given12 micrograms of DDAVP on the evening of 13 October and again the following morning. By this

	stage he was pain free and required no further factor 8 or DDAVP.
03/02/1982	Letter from GRO-B - .....although he feels well his enzymes are slightly raised and I suppose he must have developed non A non B hepatitis. I will notify Oxford and keep an eye on him though I am reluctant to worry the patient too much.
03/02/1982	Letter from GRO-B to patient's parents - .... 'I think I may have suggested that we would see him again in about six months' time but partly because of his hip and partly because of a minor change in the blood tests last week. I would like to see him again the clinic on Thursday 25th February'.....
20/10/1983	Letter from GRO-B - .... 'there was no enlargement of liver or spleen'.....
15/09/1994	Letter from GRO-B to patient – 'I understand that you wisdom teeth need to be removed and I will arrange this with Mr Cannell. As we have not met for a long time I am enclosing an appointment for you to attend my clinic so that we can review your condition before surgery.
15/09/1994	Letter from GRO-B - Thank you for your letter about this young man who has mild Von Willebrand's disease. It should be possible to perform the operation under DDAVP and tranexamic acid cover and I agree that it would be best to do this in hospital under G.A. As far as the bed is concerned I suggest we discuss this when you know the proposed date of surgery. Meanwhile I have sent him an appointment for review in my clinic'.
21/09/1994	Letter from GRO-B to patient – 'you will be glad to know that as expected your anti HIV test is negative, and there is also no evidence of infection by either Hep A or B. I am asking our haemophilia nurse specialist GRO-B, to arrange for the completion of Hep A and B vaccination, which we certainly need to start before your wisdom teeth are removed' 'As expected the hepatitis C test that we discussed together was positive, proving that you have been exposed to this type of hepatitis at some time in the past.
21/09/1994	Letter from GRO-B – 'This patient with Von Willebrand's disease has been under my care for many years but not been since 1985'. 'Since his last visit the Hep C virus test has been developed and as expected Ian's result is positive. I have tried to explain the nature of his mild hepatitis to him and I am pleased to note that his liver function tests are normal, although the HCV is as

	expected positive. We have also re-checked his HIV test, which is as expected negative and we can now proceed to his dental extractions'.
23/11/1994	Letter from GRO-B - ..... 'and he came to see me last week for further counselling related to his hepatitis c infection.....'... 'I have reassured him that currently all is well and have explained the natural history of HCV, the reasons for his previous infection, the very low risk of sexual transmission and the comparatively frequent prevalence in the normal population. I have also explained that the virus may be dormant at the moment but could be re-activated in the future even though this seems unlikely. I have also explained the need for regular follow up and have warned him against alcohol abuse. We have now arranged for hepatitis B and A vaccine to be given and have issued him with a Haemophilia Society booklet on hepatitis c infection and will see him again in three months time for further discussion'.
22/02/1995	Letter from GRO-B – '......I am pleased to report that recent tests tend to confirm that his hepatitis c infection is dormant. In particular he has a negative HCV RNA test which looks for active viral replication and I have confirmed that there is a family tendency to hyperbilirubinaemia which his father and sister also have....'
07/02/1996	Letter from GRO-B – '....his haemoglobin and LFTs are normal and as you know I do not believe that he has suffered any ill effects from his hepatitis c virus infection. At the end of our interview GRO-B questioned me closely about the treatment that he received in 1981 which we believe led to his hepatitis and I tried to explain why it had been necessary to treat him with blood products. He also asked me why it had taken until 1994 to discover that he had contracted hepatitis c and I explained that the virus was only discovered in the last five years or so, and that it had not been realistic to review the treatment records of every patient seen since the introduction of concentrates. I discussed that we had agreed together that we would not follow him up after 1985 and tried to explain that once he had come back to the hospital for his wisdom teeth to be extracted that I had taken the appropriate action'.