Witness Name: GRO-B
Statement No: WITN1407001
Exhibits: WITN1407002 - WITN1407008
Dated: January 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 GRO-B and live at GRO-B. I am single and I live alone. I am unemployed and signed off from work for health reasons.

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

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 suffer from severe Haemophilia B, also known as Christmas disease, with a baseline FIX level of <1% (normal range 50-100%). My mother was a carrier for Haemophilia B and at birth I was tested for it at GRO-B

GRO-B but the test came back negative. When I was around two years old, my mother thought it best for me to have another test and this showed that I was positive for Haemophilia B.

5. I was initially on a two hour plasma infusion drip as treatment for my Haemophilia. From around GRO-B my treatment was changed and I received Factor IX as seen in the clinical notes attached at Exhibit WITN1407002. I have been on home treatment and self administering since I was about GRO-B.

6. After being diagnosed at GRO-B I was then treated at GRO-B I was transferred to GRO-B GRO-B under Dr Colvin in or around GRO-B, which is now known as the GRO-B. In or around GRO-B my day to day care was transferred to Dr GRO-B, Consultant Haematologist and Dr GRO-B Senior Consultant at GRO-B GRO-B; however I still attended six monthly or annual checks with Dr Colvin. I attended GRO-B for dental surgery.

7. I was infected with Non A Non B Hepatitis from the blood product (Factor IX) that I received to treat my Haemophilia.

8. No information was given to me (GRO-B) or to my parents when I was put on to Factor IX treatment.

9. During one of my six month check ups, I think that Dr Colvin told me that I had Non A Non B Hepatitis. I believe it was around 1986 or 1987. The first reference that I can see to Non A Non B Hepatitis in my medical notes is in a letter dated 2 July 1987 which is attached at Exhibit WITN1407003.

10. During this meeting, Dr Colvin did not know what to say to me as the infection was all very new to the hospital too. I remember that Dr Colvin told me that my infection was *'unavoidable'* as they had to get the blood from somewhere. I was not told of any way to manage the infection but simply told

there was a risk of infecting others through sexual activity, using a razor, sharing needles or the transfer of blood. I was living with my girlfriend at the time so this became difficult to manage at home and I had to be very careful. There was no available treatment at the time of my diagnosis.

11. I do not think that Dr Colvin could have provided information earlier as he did not seem to know much about it so he could not advise what would happen.

12. From my medical notes, I see that I had a long meeting with Dr Colvin on 12 July 1995, which is when I believe that I was told about Hepatitis C (which is the new name for Non A Non B Hepatitis). I attach a letter from Dr Colvin to Dr GRO-B dated 18 July 1995 and Dr Colvin's handwritten clinic notes which state that I was 'anti HAV positive, anti HCV positive (first positive result 1990), anti HIV negative, LFT's normal – last abnormal 1979, and HCV must have been positive since mid 1970s' which are attached at Exhibit WITN1407004.

13. However, I remember about the time of my infection, or within a few months, Dr GRO- told me, off the record, that she did not know why Dr Colvin had given me that blood, as there was better blood out there. She did not know why I was given that particular type of Factor IX. From my recollection, she indicated that I should have been given heated blood products, or other non-infected blood, which was available at the time. However, I only received heat treated Factor IX in the early 1990s.

Section 3. Other Infections.

14. I recall receiving letters from both Dr Colvin and from Dr GRO-B advising me that I had an additional risk of contracting vCJD. The letters asked me to select if I wanted to know more information about the virus, which I did. I attach various documents regarding vCJD, including the initial patient information sent to me dated 20 September 2004, my Exposure Assessment Form dated 29 September 2004 and a further update letter dated June 2009 as seen at Exhibit WITN14070005.

Section 4. Consent

15. I think that I knew that my blood was tested for HIV and HCV and I assume I gave my consent. I always gave my consent for blood tests and I was usually told they were testing Factor IX levels in my blood. However, I only knew what they were testing me for if they told me beforehand. I was only given my results at the next six monthly checks and was not called back earlier.

16. I am not aware that there was any testing for the purposes of research done on me, however, in my medical records Dr Colvin sent my laboratory data to Dr GRO-B on 12 January 1984, and I attach the letter at Exhibit WITN1407006. I am not sure if I was told about this.

17. In 2000 I took part in an open study to compare the safety and efficacy of Replenine virus-filtered and Replenine in severe Haemophilia B patients. I also took part in the BYOND trial which ended in 2015. I attach copies of documents relating to these trials at Exhibit WITN1407007.

Section 5. Impact

18. When I was told about my infection I was young and carefree so I was not really bothered about the infection. I didn't have any physical symptoms and as the doctors did not really know much about the infection either, I didn't worry.

19. It was only when I got older that I took the infection a bit more seriously as I became more aware of the potential implications.

20. When treatment for Hepatitis C first became available in around 1990 I did not take it, as all tests I had regarding the virus and my liver came back as normal, I knew there were horrible side effects from the treatment and also only a 50/50 chance of success in clearing the virus.

21. I eventually agreed to being given Ribavirin and Interferon as the chances of beating Hepatitis C became a lot higher, although the treatment had really horrible side effects. My treatment began on 17 August 2010 and initially it seemed to be working, however, after about four months it was noticed that I had become severely anaemic, and after five months I was extremely fatigued and out of breath from even just speaking a sentence. I also suffered from continuous headaches every day of the treatment period, which nothing helped. I was told Ribavirin toxicity caused this.

22. I was told that I needed a blood transfusion at this point, however I refused it. I was taken off the Ribavirin treatment for about a month and my blood count improved and I felt much better.

23. I then started taking Ribavirin again and after about 12 months I was told that I needed a blood transfusion again. However, I knew that I had almost finished the course, so I refused it.

24. After the treatment course my Hepatitis C count was zero. I had another blood test a month later that also came back as zero. I felt very positive, however, what would have been my penultimate blood test then showed that the Hepatitis virus was still in my body. It was very upsetting news just when I was feeling optimistic and it took a lot out of me.

Impact on private, family and social life

25. I was in a relationship and we had started going out when I was GRO-B. In my mid 20s I began taking the infection more seriously. My girlfriend wanted kids but I didn't want to pass my Haemophilia on to my kids or risk infecting them with Hepatitis either; I did not know the risks of passing on Hepatitis C to any kids. This relationship ended due to this.

26. I struggled getting girlfriends after this due to having Hepatitis C as people did not want to get involved with me. I found it hard.

27. Hepatitis C did not really affect my family life. I did not have a close relationship with my parents anyway so it didn't affect our relationship and none of my siblings have Haemophilia.

28. My infection has not had much of an effect on my social life either, as I have not really told anyone; only a few dear friends know about my infection. With the recent news about the Inquiry, however, a few people have put two and two together but they do not ask me to my face.

29. I never really suffered any stigma as I always kept my infection very quiet. It is my business and no one else's so I never felt the need to discuss it. I managed to contain the knowledge of my infection, but I am not sure that there is even much stigma attached to Hepatitis C.

30. I am not aware of my infection having had much of an impact on anyone else. My immediate family thought the whole contaminated blood scandal was horrific but my infection specifically has not impacted them on a day to day basis. I have always attended my medical appointments on my own.

31. I was told that I was infected GRO-B, so it did not affect my schooling.

Section 6. Treatment/Care/Support

32. I did not face any difficulties obtaining Hepatitis C treatment. I was offered to trial a new Hepatitis C treatment in or around 2015 called Teleprevir, however, I declined as I had heard of people having severe skin problems from it. I was desperate to try a new treatment though as I was so close to beating the virus previously, however, I thought it was too soon to try after the last set of treatment.

33. I have been offered new treatments for Hepatitis C called Harvoni, which I believe has a 90% chance of success, however, my fibro scans are still normal to this day. My fibro scan is eight and once you get to 10 then it is

recommended that you take treatment. I am waiting for the next fibro scan this year to check the state of my liver before I decide whether or not to take the new drug. I am very happy with my current Haemophilia team in GRO-B.

34. I was not offered any counselling until The Caxton Foundation was set up, which I heard about through GRO-B. Therefore it was only in or around 2000 that counselling was offered to me, and even then I had to approach them. On reflection though, I felt that counselling at that stage was pointless and about 10 years too late, so I declined. At that stage it was more of an insult.

Section 7. Financial Assistance

35. The hospital told me that I could obtain financial assistance from the Skipton Fund. I received the Stage 1 lump sum payment of £20,000 in or around January 2005 but I was not entitled to the Stage 2 payment.

36. I then heard, GRO-B, that the Caxton Foundation had been set up and so I applied to it but I only received £500 winter fuel allowance. I also receive a disability allowance.

37. The Caxton Foundation then became known as EIBSS and since last year I receive two payments totalling around £700 a month. One payment is a means tested financial support payment of about £330. This aforementioned payment of £330 has been available for the last four or five years however I became eligible for it only last year due to the threshold being dropped. I wasn't informed of this drop and still had to apply for the payment. The other payment is about £360 and is due to me being infected by the NHS.

38. For both Skipton and Caxton payments, I had to approach and apply to them. These payments were not offered to me. The process with the Skipton Fund was straight forward as far as I can remember. I applied through the hospital, so I filled out my details on the forms and the hospital filled out theirs. Applying to the Caxton Foundation was also simple enough.

39. I believe that the Skipton Fund required me to sign a disclaimer in regards to the lump sum, however, I cannot remember if I signed it or not.

Section 8. Other Issues

40. Before the Caxton Foundation was set up I was receiving income support. When the DHSS reassessed me for this support around October 2013 they decided that I was no longer entitled to support and so put me on Jobseekers Allowance. I then received a letter informing me that they were taking me to court. The Haemophilia Sister suggested that I contact the Caxton Foundation for support and I attach her General Clinical Note at Exhibit WITN1407008.

41. The Caxton Foundation provided me with legal assistance for my appeal. It transpired that the DHSS appeals department had *'lost'* all my medical records and letters to do with my claim, so I had to get doctor's letters and medical records and show that I was on employment support allowance. My Consultant GRO-B wrote me a supporting letter date 4 November 2013. The lawyer, who was provided to me and funded by the Caxton Foundation, managed to win my appeal and I saved the vital support and allowances I was receiving. Without this I would really be struggling to this day. I do not know what I would have done and how I would have survived without this.

Anonymity, disclosure and redaction

42. I wish to remain anonymous.

43. I do not want to give oral evidence to the Public Inquiry.

Statement of Truth

I believe that the facts stated in this witness statement are true.
Signed. GRO-B
Dated......20.........................9.................

Medical Summary

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

Significant entries from medical records

1969	Diagnosis of Christmas disease made at GRO-B. Thalassaemia (trace)
1973	treated at GRO-B
20/8/1977	under care of Dr Colvin. Occasional harmarthoros (approx. 6/year) usually following slight trauma
7/6/1978	clinical note RX. 1 bottle factor IX concentrate – 560 i.u. and subsequent ongoing administrations
31/8/1978	letter Dr Colvin to GP Dr GRO-B 'at the moment his hepatitis associated antigen test is negative and liver function tests show the slight abnormalities associated with the giving of factor concentrates.'
21/8/1979	letter from mother to Dr Colvin 'please send me some more record sheets'
3/10/1979	letter Dr Colvin to GP Dr GRO-B 'he continues on home treatment as required and we will see him again early in 1980.'
14/3/1981	letter from mother to Dr Colvin GRO-B asked me this week if he could learn to inject himself and I said yes…'
22/5/1981	letter Dr Colvin to GP Dr GRO-B this patient with moderate Christmas disease has been having trouble with his left ankle and we have decided to try some prophylactic treatment for the next three months. We are starting with one bottle of concentrate a week and GRO-B is learning to inject himself.'
4/9/1981	letter Dr Colvin to Dr GRO-B GRO-B 'recently we have used prophylactic factor IX 600 units once a week and he is pleased with the result. … The Hepatitis B antigen test is negative and his liver function tests are normal for a child of his age.'
29/10/1981	letter Dr GRO-B to GP Dr GRO-B 'This boy with Christmas Disease came up with his mother to see me in outpatients today. He is extremely well on his prophylactic Factor IX concentrate, of which he has one bottle

per week. In the last 9 months he has only had three minor bleeding episodes requiring treatment.'

23/4/1982 letter Dr Colvin to Dr GRO-B GRO-B 'This young man with severe Christmas Disease had full prophylaxis until October, then about three injections a month until February and then on demand therapy in March and April. He really has no problems and would like to continue on demand treatment but can return to weekly prophylaxis if necessary'

31/12/1982 letter Dr GRO-B to Dr Colvin 'this boy came up on 29.12.1982 having had a bleed into his right thigh on 22nd. He had treated himself at home with one bottle of conc. (665u) on 22nd, one on 27th and one on 29th... I gave him 3 bottles of concentrate 1995u. Today his leg is settling down and he has given himself another 3 bottles of Factor IX conc. I feel that he should be encouraged to treat established bleeds a little more energetically – I hope you agree'

22/2/1983 Virology – screening test for HBs AG-Negative. No recent Hep A infection

14/4/1983 letter Dr Colvin to Dr GRO-B 'his liver function tests show no evidence of hepatitis though the alkaline phosphates is 194 u/l. .... (I) have arranged for our Virology Department to look for antibody to hepatitis Bs. If there is no sign of previous hepatitis B infection we should perhaps consider giving him the hepatitis B vaccine.'

12/1/1984 letter Dr Colvin to Dr GRO-B, Public Health Laboratory Service, Manchester 'I am now enclosing the relevant laboratory data and you will see that everything is completely normal apart from the minimally raised alkaline phosphatase which is probably acceptable for a boy of 16.'

13/5/1985 letter Dr Colvin to Dr GRO-B 'he told me that the heat treatment organised by Dr. GRO-B on his left ankle had been very helpful, that his general health was good and that he was working GRO-B As you know he is now back on demand treatment and has about two to three bleeds a month. He also admitted that he has not seen a dentist for years.... I enclose his latest blood tests' results and am also pleased to report that he is anti HTLV III negative. I had intended to give him my little chat about the home treatment programme and AIDS etc. but I was very busy on the day he came to the clinic and I had to rush off without giving him the usual 5 star service. If you get the chance could you give him a copy of the home treatment rules I sent you recently, explaining what they mean and what we are trying to achieve. At the same time it is obviously important to be reassuring about his own particular problem as all our own Christmas Disease patients have so far been anti HTLV III negative'

7/11/1985	letter Dr GRO-B to Dr Colvin 'I have now started GRO-B on his first dose of Hepatitis B vaccine uneventfully'
6/1/1986	letter Dr GRO-B to Dr Colvin GRO-B has now received his second dose of Hepatitis B vaccine slightly belatedly. He will receive his booster in May'
June 1986	letter Dr Colvin to Dr GRO-B Dr Colvin requested physio and heat treatment on left ankle
3/7/1986	letter Dr Colvin to Mr GRO-B 'Meanwhile you will be glad to know that your blood test was very satisfactory and showed no signs of viral infection.'
25/1/1986	gene tracking results
2/7/1986	letter Dr Colvin to Dr GRO-B 'This young man remains well enough in himself but has had some more pain in his left ankle without bleeding... As you know he works at GRO-B and is drinking about three pints of beer a day. I explained that this was probably too much for him although his liver function tests are perfectly normal since he probably has had non A non B hepatitis in the past.'
26/8/1987	letter Dr GRO-B to Dr Colvin GRO-B received his third does of HB VAX on 7/5/1986'
26/5/1988	letter Dr Colvin to Dr GRO-B 'His liver function tests are normal and I will see him again in six months' time'
15/7/1988	letter Dr GRO-B to Dr Colvin GRO-B admits to drinking at least 8 pints a day (beer)
16/8/1988	letter Dr Colvin to GRO-B – he is fit to work as a GRO-B GRO-B
2/2/1989	letter Dr Colvin to Mr GRO-B 'You will be glad to know that all your blood tests were very satisfactory and there is nothing more for us to do at the moment.'
30/8/1989	letter Dr Colvin to GP Dr GRO-B. He has been made redundant as a GRO-B
unknown	Dental extractions by Mr GRO-B
5/2/1990	Left Ankle arthrodesis (surgery) at GRO-B due to recurrent bleeding to foot led to degenerative changes (arthritis for 4 years following # ankle in childhood). 5,000 units Factor IX cover for operation. Then 11,000 units post operation. Consultant Dr GRO-B Immune to Hep B, Anti HIV – (negative)

8/2/1990	given Factor VIII in error. Reported to Dr Colvin
16/2/1990	Breathlessness due to pulmonary embolus post-operation. Given Heparin
22/6/1992	genetic analysis of blood
5/10/1993	started hepatitis A vaccination
18/7/1995	letter Dr Colvin to Dr GRO-B – long talk about Hep C virus infection. Undated handwritten notes anti HCV Pos. Ist pos result 1990. HCV RNA Pos. Anti HIV Neg. HCV must have been positive since mid 1970s
4/2/2000	took part in study to compare the safety and efficacy of Replenine virus-filtered and Replenine in severed haemophilia B patients
18/1/2002	left subtalar (ankle) fusion (arthrodesis) operation at GRO-B. Given Factor IX Replenine peri and post operatively. Continue for 1 week
7/2/2003	admitted for fusion of left ankle but already fused
20/9/2004	letter from GRO-B about vCJD
15/11/2004	letter from Dr Colvin 'you have, in the past and like many other patients, received plasma concentrate to which one of the affected donors contributed. As has been previously explained there is no evidence that variant CJD can be spread by factor concentrates and no one in the haemophilia community has developed the condition.'
June 2009	letter from Dr Colvin advising a haemophilia who was found to have evidence of the abnormal prior protein associated with vCJD in his spleen in a post mortem
11/8/2010	letter from Dr GRO-B GRO-B – his Hepatitis C infection 'was diagnosed in the late 1980s or early 1990s and is thought to have been acquired through contaminated factor IX'
17/8/2010	Peg Interferon & Ribavirin treatment
Feb 2011	clear
13/6/2011	eligible for screening for BLONG clinical trial (long-acting Factor IX:Fc trial)
19/7/2011	off IFN and Ribavirin. Achieved viral negativity at end of treatment July 2011
18/8/2011	headaches and heat rash

20/10/2011	Relapsed (ribavirin toxicity)
11/5/2011	Hep C Genotype 1b
9/11/2011	letter GRO-B to GP Dr GRO-B 'He is doing very well on the B long trial and has not had any bleeds at all. The biggest issue at the moment is that he has relapsed through his HCV treatment at the last test. He is now being considered for protease therapy. The funding for these needs to be established'
28/6/2012	Fibroscan at GRO-B. Result 6.2kPA inter Quartile Range 1.2kPA which equates to a fibrosis score of F0/F1. In the context of his diagnosis this suggests negligible scarring or fibrosis
6/11/2012	currently on the longer lasting factor IX clinical trial
3/12/2012	3000iu rFIXFc prior to multiple dental extractions
4/11/2013	letter GRO-B to whom it may concern 'In addition he has hepatitis C infection which he acquired as a result of a transfusion of infective blood products provided by the NHS previously.'
15/5/2015	General clinical note 'This chap had a fairly clean scan F0/F1 in 2012. He is keen for an interferon free strategy when available'
15/3/2016	General clinical note by GRO-B Research Trials Manager 'Unfortunately the BYOND trial is coming to an end and you have reached the 4 year anniversary. Your End of Trial visit is o0 10th April 2015… We have negotiated a deal with the sponsor Biogen, in that you will still receive the product on a named patient scheme'
10/11/2016	Dr GRO-B, Consultant Haematologist, The GRO-B GRO-B letter to support PIP application
22/11/2016	physio referral for long standing right pain hip
7/4/2017	letter Dr GRO-B, The GRO-B GRO-B 'He has been contacted by our hepatology team with a view to discussion so f further treatment which would be non interferon based. He is quite positive about this and I have encouraged him to try to get a slot for eradication therapy as soon as possible.'
14/2/2018	coughing up blood, cough++ and cold, catarrh, runny eyes. This is most likely a haemophilia related bleed due to a small upper respiratory tract vessel bleeding and is probably associated with his viral infection.
18/7/2018	Fibroscan at The GRO-B. Liver 8.6kPA inter Quartile Range 0.5kPA.

8/10/2018	Fibroscan repeated July 2018 – slight worsening from 6.2 to 8.6kPA – albeit different machine, differed operator. Discussed these results in detail. He is still unkeen to proceed with treatment – he knows door open at his request. He prefers a repeat Fibroscan in a year.