Witness Name: G G Manning
Statement No: WITN1367001
Exhibits:WITN1367002-3
Dated: November 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRAHAM GEORGE MANNING

I, Graham George Manning, will say as follows:-

Section 1: Introduction

1. My name is Graham Manning. My date of birth is GRO-C 1968 and I live at GRO-C, East Sussex, GRO-C I am divorced with two sons.

2. I suffer from mild haemophilia A. I contracted Hepatitis C, genotype 1b, after being treated with contaminated blood products.

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. When I was 9 years old I fell over in the playground at school and hurt my knee. My parents took me to A&E at The Brook Hospital in SE18 (this hospital no longer exists). They spired my knee and took blood.

5. My medical records record that I was admitted on 4 May 1978 for a left knee haematoma. The discharge summary notes that I had a history of previous bleeding disorders after cuts and tooth extractions and that my father and maternal grandfather also had a history of bleeding. At first they thought I had a Factor IX deficiency and I was treated with 4 bottles of Factor IX initially followed by another 3 bottles the following day. Directly after taking the Factor IX I had a really bad pain in my stomach, which I believe the doctors gave me something for. This was written by the doctor but he got it wrong – only my grandfather had a history of bleeding.

6. I remember the doctors telling me that the products I was receiving were from America when giving me the Factor IX. I was really excited about this because I loved all things American when I was a child.

7. There are no batch numbers recorded in my records for the Factor IX.

8. It is clear from my medical records that the hospital was still carrying out blood tests whilst I was treated with Factor IX. Following the results of further tests they concluded that I actually had a deficiency of Factor VIII. I was then treated with Factor VIII cryoprecipitate 30 units. I understand that this was manufactured in the UK and therefore think it unlikely that I was infected by this product.

9. I believe that my parents were not really aware of what I was being treated with, although my mother raised a concern when it became clear that they had treated me with Factor IX when I didn't actually need that product. I believe that she asked the doctors if it was dangerous and they assured her that this was nothing to worry about.

10. Looking back now I cannot understand why the hospital thought I had a Factor IX deficiency as I understand that the symptoms of a blood clot haematoma (which was the problem with my left knee) are not symptoms you would expect to find in a patient with a Factor IX deficiency.

11. My treating doctors at The Brook Hospital were Mr GRO-D Dr GRO-D and Dr GRO-D I believe Mr GRO-D was the Consultant in charge.

12. Although I was treated at The Brook Hospital it was Lewisham Hospital that provided both the Factor IX and the cryoprecipitate. The haematologist at Lewisham was Dr GRO-D

13. After the knee injury I was recuperating at home with my parents. They noticed that I had become very tired and said that I looked yellow. They were a bit alarmed by this but they put this down to a reaction to the keyhole surgery that had been carried out on my knee to remove the blood clot.

14. My haemophilia was considered very mild and between 1978 and 1988 I attended the Haemophilia Centre at Lewisham on a couple of occasions (for work on my teeth and an ankle problem) but was not treated with Factor VIII.

15. On 23 May 1988 I hit my elbow and had a haematoma. I attended Lewisham Hospital and was given Factor VIII. According to my UK Haemophilia Database records this was FVIII (BPL). This is now shown to me marked **"WITN1367002"**.

16. I have only received factor concentrate on two occasions which could have caused my infection: the Factor IX in 1978 and the Factor VIII in 1988. I believe that I was infected by the Factor IX which I was given unnecessarily in May 1978. After 1988 I was treated with DDAVP.

17. I believe my UKHCDO records are incomplete because there is no record of the Factor IX treatment I was given in May 1978.

18. In August 1992 my parents and I received a letter from Lewisham Hospital Haemophilia Centre which stated that I remained on their register and asked

me to attend so that my current condition could be assessed. The letter also recommended that I be vaccinated for Hepatitis B because it was a potentially serious disorder which could be transmitted by contaminated blood products. It also stated that people who had been treated in the past might have been exposed to infections and suggested that they could not ascertain whether people had cleared these infections unless blood tests were done. The letter offered a discussion regarding these issues and possible tests. A copy of this letter is now shown to me marked **"WITN1367003".** The third paragraph of this letter suggests that the hospital new about the risk of Hepatitis C at that stage albeit the letter does not explicitly refer to Hepatitis C.

19. I felt that the letter was a standard letter sent out to all haemophiliacs and that it was not really aimed at me. I was a mild haemophiliac who had only received treatment with concentrate on two occasions at that point and had not visited the Haemophilia Centre for years. I thought the letter was really aimed at severe haemophiliacs who received regular treatment. At the end of the letter there was a slip which was to be returned to the hospital to indicate whether you wanted to attend for testing or not – it did not suggest that it was a big deal or that patients should attend for testing because it was something serious. I note that the letter was actually signed by Dr **GRO-D** (not copy signed) which I now think is a bit odd. In hindsight it seems to me that they knew at that stage that I was infected.

20. **GRO-C**

GRO-C the Centre had asked after me a number of times and told **GRO-C** that they wanted to see me.

21. I note from my medical records that Lewisham sent a bulletin about Hepatitis C in 1993 stating that anyone who had received blood products should be tested. I do not recall seeing this letter and cannot say whether I received it due to the passage of time.

22. I visited the Haemophilia Centre in October 1995 and was tested for Hepatitis C. I was not told that I was being tested for Hepatitis A, B or HIV.

23. I went back to the clinic in November 1995 and I was told that I had tested positive for Hepatitis C but that the good news was I was negative for HIV. I was completely devastated and couldn't believe it. GRO-D informed me of the diagnosis and she advised me to keep alcohol intake down to 21 units a week. I was told there was a slight risk of the transmission by sexual intercourse and that I should not share razors or toothbrushes. I was advised that I would need regular check ups and that I should have the Hepatitis B vaccination. I was told nothing about the prognosis of the infection other than that you could get liver cancer. I was told they didn't know how I had the infection, I just did.

24. I was so upset and so angry when I was told about my diagnosis. I remember being in the hospital and hearing the alarm on my new company car going off but just not caring because I thought I was going to die. I called my mum on the way home and I burst into tears. Then I stoically went back to the office where I lied about where I had been. I went to my parents' house and they took it very badly.

25. Shortly after my diagnosis my mother phoned the Centre to ask for more information and was just told that they had a number of patients with Hepatitis C who had liver problems.

26. In December 1995 I received a letter from the Centre confirming that my re-test for Hepatitis C was positive and that I was HIV negative. I did not know that I had been re-tested for HIV.

27. In I was 2000 tested for Von Willibrands disease. This test was negative.

Section 3: Other Infections

28. I have potentially been exposed to vCJD. Even if I clear Hepatitis C I won't know whether I am clear of everything.

29. I am very concerned about the risk of vCJD.

30. I accept that there are letters in my medical records which mention the risk of vCJD. I do not recall seeing these but I suspect they were received at a time when mentally I was not able to deal with looking at them.

31. I have received very little information about this although I understand there is no test, so I don't know where I stand with this.

Section 4: Consent

32. I consented to be tested for Hepatitis C in October 199. They did not tell me they were testing me for Hepatitis A, B or HIV, which my records show they were.

33. I was shocked when they told me that I had tested negative for HIV because I had no idea they had even tested me for it.

Section 5: Impact

34. When I was at school I was always exhausted and would become muddled and confused very easily. In hindsight my exhaustion and brainfog definitely affected my school grades. I wondered if everyone felt like this.

35. I started drinking heavily following my diagnosis, I thought I would never get married and would die extremely young. I couldn't tell any of my friends. I got extremely depressed.

36. I was used to keeping secrets because I used to keep my haemophilia secret in the mid 1980s because I always wondered if I might have been infected with HIV.

37. Whenever I brush my teeth or shave, I disinfect the entire sink every time. This started immediately after my diagnosis. I was terrified of transmitting the infection to someone else and would not even leave my toothbrush near my parents, wife or children.

38. I couldn't tell anyone at work. I have worked in the same company for 24/25 years as a salesman selling office equipment and, at that time, I was terrified of them finding out. The company had a pension scheme which I wanted to transfer my private pension into. At the same time I was being offered life insurance and private medical care. I told them that I was not interested in private medical care because I was afraid someone would find out about my diagnosis. I was able to obtain life insurance but only to the value of my pension pot (£100,000) which was much lower than the scheme offered to my colleagues.

39. From 1995 to 2010 I was seen at Lewisham Haemophilia Centre and had regular blood tests. I was just told that these were for Liver Function Tests and was always told that the results were much the same a previous results. It would become routine for me to go to appointments and the nurse to say "what are you here for". I was made to feel like cattle being herded through the system.

40. My diagnosis impacted on my relationships. I met my ex-wife in 1996. I couldn't tell her about the diagnosis for over a month, and when I finally told her she broke down. We couldn't tell anyone – not even her family.

41. My ex-wife used to come to my consultations with me and we would sit in the waiting room with no one speaking to each other. At that time I still thought it was something that had only happened to me. It made me feel like a leper.

42. When I got my first mortgage I had to go to a specialist mortgage company. I eventually managed to get one with life insurance but this was extremely expensive to take out. The premium was about £75 a month with Zurich.

43. I was doing well at work and continued to push myself. Every single day I would think about having Hepatitis C and the risk of infecting others and I would wonder whether I would live to see tomorrow.

44. In June/July 2001 I had investigations following a serious pain under my rib cage. Tests were carried out at Lewisham A&E and it would found I had gall stones and my gall bladder had to be removed. Tests were carried out on my gall bladder which showed I had chronic collop with ulceration. This is common in patients with Hepatitis C but I was not advised of this by either Dr Tillyer or Dr Alan Gottleb.

45. When my wife and I discussed having children we went to see **GRO-D** She said that the risk of passing on the infection to the baby was about 5%. She then told us that there was lots of other things that could go wrong in pregnancy/birth which had a much higher risk than 5%. I did not find this very helpful or comforting.

46. Whenever my children would hurt themselves my wife would shout to them 'don't go near him' referring to me, as she was worried I would infect them. This was extremely difficult for me.

47. In or about 2008 I was prescribed Fluoxetine for my depression. This worked for about a year but then stopped working and I was moved onto Sertraline. This had side effects including mood swings and I eventually stopped taking these and started having counselling instead. I now take Vensirxl and Quetiapine.

48. By 2010 my relationship with my wife was strained. I drank a lot and found the symptoms following treatment difficult to deal with

49. I have been having treatment for my mental health for at least 10 years either by way of medication or therapy and am currently awaiting an appointment with the Brighton Mental Health Team.

50. I feel like my parents blamed themselves for my infection. My mother passed away earlier this year.

51. My haemophilia has never really been a problem; it has only been the Hepatitis C.

52. In about 2005/6 I found the campaigns around contaminated blood and realised that I wasn't on my own I found this hugely helpful. I realised that I was not alone and that there were people worse off than me who had contracted HIV or had already died from their infections. Instead of being angry about what happened to me I am now angry about what it has done to the other families affected.

53. I have felt the stigma of my infection over the years but not as much as others whose stories' I have heard. I knew haemophiliacs were having bricks thrown through their windows long before I had been diagnosed with Hepatitis C.

54. When I was diagnosed (and for a long time after) I was terrified of friends/family finding out and what they might think. The cover up of this scandal is just as bad as it compounds the feeling that those infected are somehow dirty or to blame.

Section 6: Treatment/Care/Support

55. I was desperate to have treatment to get rid of the Hepatitis C infection. Following my diagnosis I was treated for 6 months with anti viral medication. This was interferon mono therapy and took place between October 1996 and February 1997. I believe that they took me off the treatment early because it was not working.

56. I was a "non responder" to this therapy after 10 months.

57. The side effects of treatment were difficult and I continued to work throughout my first treatment because no one at work knew about my condition. I have had flu like symptoms ever since first taking interferon.

58. After the first treatment failed I got very angry that I still had the virus and felt overwhelmed.

59. The second treatment (Pegylated Interferon with Ribavirin) was much worse in terms of side effects. I started this in July 2003 and the treatment lasted 48 weeks. This had serious side effects including general aches and pains, flu like symptoms, mood swings, depression, excessive anger and these continued for about a year. The symptoms decreased once I stopped treatment but did not stop. They mainly continued to affect me in the afternoon which was when I had taken the antiviral medication when I was on it. Flu like symptoms and tiredness set in at about midday every day.

60. This was a huge moment for me and I have never been the same person since that second treatment. There is a Graham before this treatment and a Graham after this treatment. I am a different man.

61. I was totally out of control. I had horrendous depression and would have wild mood swings. My ex wife raised my behavioural issues at the time of our divorce.

62. It was a living hell. I had to inject myself and then take tablets. I would feel dreadful every day.

63. After the first 6 months I was told that there was no trace of the virus and to carry on with the treatment.

64. I had scabs on the top of my head. It was like having flu every day. I was angry, out of control, had mood swings. I couldn't sleep and would end up listening to music at 3 am crying.

65. In the last 6 months of that treatment I felt suicidal but I managed to get through it. A month or two after I finished the treatment the virus came back.

66. For this treatment I was under Dr Tillyer (Lewisham) and Dr O'Donoghue and Dr Mairs (Royal Free). Funding was given to the Royal Free for my treatment but I ended up being treated at Lewisham because it was more local.

67. I had never been offered counselling around my treatments. It was mentioned in September this year around the time of my most recent treatment but nothing ever came of it.

68. I have my own mental health team in Brighton who look after me and prescribe my anti-depressants.

69. In September 2018 I started treatment with Zepatier which contains two drugs. I noticed the difference within a week. I felt completely different. I still have bouts of depression but I have felt more clear headed, less fatigued and my flu like symptoms have gone since starting this treatment. It is a 3 month treatment and I am hopeful that when I am tested in February next year I will have cleared the virus.

70. It has taken from 2010 to 2016 to get onto the treatment (which is a clinical trial). Initially there was a funding issue. Then when funding came through in 2016 I was not in a good place mentally to consider treatment particularly given the side effects I had suffered previously. This year my depression has been very bad even whilst taking antidepressants and I decided that it was time to do something about the Hepatitis C. St Thomas' gave the ok for the treatment to go ahead in 2016.

71. I had an ECG before taking the new treatment which came back fine. However, I had been having very bad heart palpitations and I had to come off the medicine for 2 days. It felt like I was having a heart attack and I had to come off the treatment. I was put back on the treatment after a further ECG. They told me if it happened again then to go to the hospital and be monitored.

72. My blood pressure has also gone through the roof recently. I don't know if this is a side effect of the treatment.

73. I will go back in February 2019 to find out if I have been given the all clear.

74. I can't take the Quetiapine whilst I'm on the Hepatitis C treatment.

Section 7: Financial Assistance

75. The Caxton Foundation was initially something I knew nothing about. When I was told about it I applied for a contribution towards a car because I needed a car to get to work.

76. It was an extremely long winded process and you wouldn't hear back from them for 6 weeks, as they had a meeting to decide if you were worthy. They also required 2 quotes before they would consider a request and then they could turn you down if you had had your "quota" for that term.

77. I received a Stage 1 payment of £20,000 from the Skipton Fund in 2004. Under the previous scheme you needed to be nearly at death's door to qualify for the Stage 2 payment.

78. My prescriptions are free up until 27 November 2018 but I then need a new card. With the Skipton Fund they used to arrange the pre paid card and send it to you. I have emailed EIBS, the new fund, about this but have not yet had a response.

Section 8: Other Issues

79. We need to find out who was responsible and why they made the decisions they did. I think the names of everyone responsible should be read out, alive or dead,

80. I believe everyone should have a shot at the treatment. However for me it is bitter pill to swallow that people who have been reckless with their health through their own behaviour and abuse drugs are being offered the treatment before people who have been infected through no fault of their own.

81. I believe the Government should be providing life insurance. There are families in dire straits because they have not been able to obtain life insurance and who risk losing their homes if one of them dies because they simply do not have the means to meet the mortgage repayments and have

been unable to protect against this by obtaining life insurance through no fault of their own.

82. As so many people are struggling financially and so many people won't see the end of this Inquiry payments need to be sorted out quickly, .

Anonymity, disclosure and redaction

83. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

84. I confirm I do wish to be called to give oral evidence.

Statement of Truth

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

Signed.. GRO-C ....

Dated 23/11/18

MEDICAL SUMMARY

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

15.06.1978	Letter from T Cuddigan to Lewisham. At about this time we received an unclotted sample of blood for testing and found his kaolin cephalin time some 20 seconds longer than normal. Correction experiments showed that this could be shortened to normal with normal plasma or serum but not by adsorbed plasma and in view of this I believed he must be Factor 9 deficiency and you kindly sent us some Factor 9 concentrate. At the same time a sample was taken to Lewisham where they found that the deficiency was not corrected by haemophiliac plasma. He had by then received several bottles of 9 concentrate and in view of your findings we continued with Cryoprecipitate until he had completed a week's treatment....
20.07.1978	Letter from Lewisham to patient's parents stating they think patient has mild haemophilia but want to repeat blood tests in the autumn.
10.10.1978	Letter from Lewisham to patient's parents confirming he had Factor VIII deficiency almost certainly due to haemophilia.
28.05.1993	Letter from Lewisham enclosing patient bulletin containing information about Hepatitis. States that everyone who has received blood products should be tested for Hepatitis C.
23.10.1995	Annual review. Tested for HIV, Hepatitis A, B and C...
Undated	Patient told Hepatitis C positive result. Counselled. Very angry as has had minimal exposure to blood products. Advised re curtailing alcohol intake...Sexual transmission. Need for regular follow up. Repeat Hepatitis C. Letter re result.

09.11.1995	Letter from Lewisham to patient. Following attendance at annual review Hepatitis C test is back but needs repeating.
20.12.1995	Clinic notes. Hepatitis C genotype 1b....Letter...HIV Neg.
20.12.1995	Letter from Lewisham confirming patient Hepatitis C, genotype 1b positive with evidence of viral activity in the blood.
27.12.1995	Patient phoned. Brief discussions of Hepatitis C diagnosis. Wished to know significance of genotype 1b.
08.01.1996	Clinic notes. Discussed risks/benefits of interferon therapy. Needs Hepatitis A/Hepatitis B vaccination courses. Bulletin '95 Hepatitis C info given and discussed with patient.
March 1996	Sent Hepatitis C bulletin by Lewisham.
24.06.1999	Letter from Lewisham. Graham has recently married and is trying for a family at the moment. He understands there is a small risk of transmission to his wife and this is one of the things he finds most difficult to cope with. He is very well informed about Hepatitis C and reads the Haemophilia Society reports about this regularly.
07.12.1999	Letter from Lewisham to GP. Normal liver function tests in June. No symptoms referable to Hepatitis C.
17.07.2003	Letter from Lewisham. He is aware of the changes of him actually responding to treatment tare very low and has discussed this frankly with Dr O'Donohue and myself today.
23.10.2003	Letter from Lewisham. His Hepatitis C RNA checked on 10 October came back negative which has made Mr Manning an extremely happy man. This is therefore the go ahead to continue with the 48 weeks of treatment.

08.04.2004	Letter from Lewisham. He continues to be tolerant of interferon therapy which he attends on Saturday and gets flu like and down symptoms on Sunday but is well for the rest of the week.
05.12.2003	Letter from Lewisham. Graham is continuing to tolerate treatment reasonably well apart from some tiredness and insomnia. He has not needed to take any time off work.
20.09.2004	Letter to patient to confirm "at risk" of vCJD.
19.11.2004	Letter to GP to confirm patient in "at risk" group for vCJD because he had been treated with UK plasma concentrates between 1980 and 2001.
09.03.2005	Letter from St Thomas' to patient confirming Hepatitis C RNA level shows significant amount of viral copies in blood therefore he has not cleared the virus from his liver.
20.04.2005	Letter from St Thomas' to GP. He remains fairly physically well but is extremely concerned because he seems to have become very depressed recently with sudden mood changes....He experienced the same sort of feelings that he did when he was on pegylated interferon and ribavirin and is consequently concerned it may be a late effect of treatment. I think this is highly unlikely but what I fear is he may be suffering from endogenous depression and since this can be precipitated during the treatment.
13.11.2007	Letter from Lewisham to GP. Feeling rather depressed and fed up following his unsuccessful Hepatitis C treatment and as a result has not attended for any follow up at the Haemophilia Centre or with Dr O'Donohue for the last couple of years. I understand that you successfully treated his depression with antidepressants for 3 months last year, but his depression has

	recurred since coming off treatment.....Advised that depression could still be as a result of the interference on treatment. Advised to see you in connection with re starting anti depression therapy and/or counselling for this. Hepatitis C PCR re checked.
24.09.2009	Letter from Lewisham to GP. He has been troubled with symptoms of tiredness, a flu like illness, extreme fluctuations in mood and sometimes suicidal ideation. He has been on anti depressants for the last couple of years with little benefit. I have explained to him that it is unlikely to be related to his previous treatment for Hepatitis C with pegylated interferon and ribavirin about 2 years ago.
24.09.2009	Letter from Lewsiahm to Life Insurance Company.....The natural course of chronic Hepatitis C is of gradual progression to end stage liver disease requiring liver transplantation. He is currently being actively monitored and his recent liver function tests remain within normal limits.
07.12.2009	Letter from counsellor to life insurance company. I have been seeing Graham since June this year. He attends regularly, usually weekly. I completed my initial assessment in June 2009, and Graham admitted that from time to time he has suffered suicidal thoughts. However it was also established that there has never been any intention to carry out those thoughts.
23.06.2010	Letter from Lewisham to GP. I understand he is undergoing regular counselling for management of psychological problems. Last liver function test was within normal limits.....We will arrange to give him a booster Hepatitis C. V vaccination he remains non immune to Hepatitis B. We will also refer him to the gastro team at St Thomas' for arranging a fibro scan for a valuation of Hepatitis C liver disease.

23.06.2010	Referral to St Thomas'. He had contracted Hepatitis C due to blood product administration for haemophilia in the 1970s. He failed to respond with Interferon mono therapy October 1996 and relapsed post pegylated interferon and ribavirin 2003.
10.08.2010	Seen in combined Haemophilia/HepatitisClinic at St Thomas. Referred for further evaluation of Hepatitis C. Known to have mild haemophilia A and is on demand treatment for this. First treatment known to have been at Brook Hospital between 1978 and 1979 for knee injury. This was when he was aged 8 to 9 and he contracted Hepatitis C after this....he had monotherapy in 1996 which lasted for 10 months and at that time he was said to be a non responder. In 2006 he had pegylated interferon plus ribavirin with 12 months treatment but relapsed. He confirmed that the first 6 months of treatment were fine but that during the second 6 months he experienced major side effects feeling generally unwell with depression which required no treatment. He continues to have symptoms from this and continues to see a counsellor due to his marriage problems. He did try some antidepressants but these were not affective.
14.12.2010	Letter from St Thomas' to Lewisham. The earlies that he could have contracted Hepatitis C is 1978...I note in his treatment history he had standard interferon monotherapy from 1996 to 1997 and was a non responder. In 2003 he had a 48 week course of Pegylated interferon plus Ribavirin; was negative for 6 months, but unfortunately relapsed. His fibroscan in clinic today showed a liver stiffness measurement of 5.3 kPa which indicated that he is non cirrhotic....Mr Manning is Hepatitis C genotype 1A and his viral load is 3169047 iu/ml. With respect to his treatment it does seem that he would be a good candidate for the new protease inhibitors that are due to be licensed next year....

Feb 2011	Letter from Lewisham to patient. Another donor developed vCJD but Mr Manning not given blood from this donor.
March 2011	Letter about development of potential test for vCJD. Confirms that the patient is considered an “at risk” patient.
19.09.2012	Letter from Lewisham to GP. He has been well with no bleeding symptoms since last clinic visit in 2010. He attends the Network Hepatitis C clinic at St Thomas' hospital and awaiting to be commenced on the new protease inhibitor therapy in combination with Pegylated Interferon/Ribavirin treatment for Hepatitis C liver disease.
03.05.2013	Letter from St Thomas'. Patient has been started on antidepressants.
28.01.2015	Letter from St Thomas'. Feeling generally tired. He will continue on 6 month Hepatitisatic carcinoma screening with fibroscan yearly.
15.08.2017	Letter from St Thomas'. He continues to feel tired and will be reviewed by the mental health team. He is now on Venlasaxine. His ultrasound from 1st August is unchanged and his bloods from today are stable. His fibroscan from today is 7.4.