

Witness Name: **Mark Anthony STEWART**

Statement No: WITN100000

Exhibits: WITN1000002_ WITN1000034

Dated: **6 September 2019**

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MARK ANTHONY STEWART

I provide this statement in response to a request for evidence made by the Inquiry under Rule 9 of the Inquiry Rules 2006.

I, Mark Anthony Stewart will say as follows:

Introduction

1. My name is Mark Anthony Stewart. My date of birth and address are known to the Inquiry. I was born with von Willebrand's disease and I was infected with Hepatitis C (HCV) and exposed to variant Creutzfeldt Jakob Disease (vCJD) as a result of being given contaminated Factor VIII whilst under the care and treatment of NHS clinicians.
2. My father, Angus Stewart (date of birth GRO-C 1938) and my eldest brother, Angus Stewart Junior (date of birth GRO-C 1965), were also born with von Willebrand's disease and similarly infected with HCV as a result of being given contaminated Factor VIII. As a consequence, they are no longer alive to tell their own stories. My father passed away due to HCV and liver cancer on 2 September 2002 aged 64 and my brother Angus passed away on 28 December 2013 aged just 48 having suffered from liver cancer, had a liver transplant and then fought further cancer of the lung that spread to his bones.

3. I firmly believe that my father, brother and I were deliberately infected with HCV by NHS clinicians who used us (and others) as unwitting test subjects in their pursuit of clinical/academic research on previously untreated patients ('PUPs') and the furtherance of their individual reputations and careers.

How Infected

4. My von Willebrand's has always been categorised as mild in severity and I recall that my father and Angus Junior were categorised as being mild to moderate in severity. As far as I am aware, none of us were ever given blood products to treat ourselves at home at any point in the 1960's, 1970's or 1980's.
5. As a result of our von Willebrand's, in our early years Angus and I were both under the care of Great Ormond Street Hospital. However, in around 1978, when I was 10 years old and Angus was aged 13, we were referred to the Haemophilia Centre at the Royal Free Hospital in London where the Consultants/Directors in charge of our care were Professor Peter Kernoff and Professor Edward Tuddenham.
6. Thereafter, as children Angus and I attended the Royal Free Hospital on a regular basis, both for scheduled appointments for routine check-ups and if and when we ever sustained an injury that led to bleeding. Both Angus and I would also have occasional nosebleeds and our parents were told that if a nosebleed did not stop after 20 minutes then we would need to immediately go to hospital by ambulance. This information was also given to our schools.
7. Due to the frequency of our visits to the Royal Free Hospital, Angus and I gradually developed friendly relationships with the hospital staff, particularly the nurses called Debra, Christine and Barbara, who I believe still work there today. I distinctly recall that the staff referred to us as the "special" children and that made us both feel better about having von Willebrand's disease and everything that came with it. At the time, the staff appeared to be extremely kind and helpful and as a result both Angus and I felt very comfortable about spending time at the hospital when we needed to. However, looking back now, I do not know what each individual member of staff may have known or been aware of at the time of our infection and thereafter.

8. As an adult, whenever I have required any treatment at the Royal Free Hospital, I have had to personally collect my medical records from the Haemophilia Centre and take them with me to the relevant department.
9. In November 2006 I was having some treatment in hospital and as usual had my medical records with me. As I was waiting to be seen I decided to have a look through my records and found some old blood test results from the Virology Department at the Royal Free Hospital. These included the results of testing for HCV antibodies by EIA and by RIBA. I carefully looked through them and realised that these results did not state that I was "negative".
10. In particular I found two early results, one dated 2 June 1992 that read "**POSITIVE**" for HCV antibodies by EIA and "*INDETERMINATE RESULT*" for HCV antibodies by RIBA (WITN1000002) and another dated 25 November 1994 that stated "**POSITIVE**" for HCV antibodies by EIA and "*REACTIVE*" for HCV antibodies by RIBA (WITN1000003).
11. I also found results dated 1 December 1999 from which it appears I was tested for HIV, HCA and HCB but not HCV (WITN1000004) and results dated 25 November 2002 that stated that HCV RNA was not detected (WITN1000005).
12. I have since realised that whilst the results dated 25 November 2002 have my name on the top, they refer to a completely different hospital number. My hospital number is 217031, but the hospital number on the 25 November 2002 results is 217068. I am concerned by this, not only because of the potential for me to have been given the incorrect results, but also because it could mean that there is somebody else out there who has been infected and may not know about it.
13. Reading all of these test results was extremely worrying and I was really confused as I had no idea when or how I could have contracted HCV and had not been told that my blood was being tested for HCV or other viruses, let alone given my consent or been told of the results.
14. I decided I had no option but to speak to the doctors at the Haemophilia Centre at the Royal Free Hospital and seek an explanation for what I had found in my

medical records. The doctors told me that in light of my concerns they would retest me for HCV. I provided fresh blood samples on 20 December 2006 and 18 January 2007, which were sent for analysis. The results came back on 18 January 2007 and both samples were positive for HCV. This was the first I knew that I had active HCV but I did not know how long I had been infected for or what damage the virus may have done to me. I could not believe what was happening.

15. My previously stored samples from 1999 and 2002 were then retested on 7 February 2007. The results also came back as positive (WITN1000006) but what is notable is that the 2002 sample was dated 21 November 2002 and not 25 November 2002 as recorded on the test results bearing the incorrect hospital number 217068 (WITN1000005).
16. I have since obtained my available medical records and gone through them in detail. When doing so I came across a letter dated 14 February 2007 from Dr Tanzina Haque, Consultant Clinical Virologist to Dr Pratima Chowdary, Consultant at the Haemophilia and Haemostasis Centre at the Royal Free Hospital (WITN1000007) which stated:

"This patient was found to be hepatitis C (HCV) IgG antibody positive in November 2002. However, HGV RNA was not detected in serum tested around the same time (November 2002). We did not receive any follow up sample until recently. Blood taken on 20/12/06 and 18/01/07 was tested by our new PCR assay and both samples contained over a million IU of HCV RNA per ml (Genotype 3a). This led to retrospective analyses of the stored sera from December 1999 and November 2002, and both sera were found to be positive for hep C RNA (623,122 IU and 799,692 IU respectively). We have also genotyped the virus in these stored samples and both had the same genotype (3a) of virus as seen in 2006 and 2007 sera.

The initial RNA test in 2002 was performed by an earlier version of the PCR assay which possibly gave a false negative result. However, at this stage we cannot exclude any labelling or sampling errors.

I am extremely sorry for this mistake. If a patient is found to be HCV antibody positive and RNA negative, (as was seen in this case in 2002), please send a follow up blood sample to confirm these results. It is recommended that patients with these discordant results (Ab positive, RNA negative) should be tested yearly for HCV RNA to monitor any change."

17. This letter evidently blamed the PCR assay that they had used in 2002 for failing to identify that I had HCV but does not provide any information as to when I was first infected, when the new PCR assay became available or why retrospective analysis was not carried out on my stored samples sooner. It must have been known that the new PCR assay had improved the accuracy of the test results and I cannot understand why I was not automatically recalled for further testing.
18. I desperately wanted to know how and when I had been infected with HCV, particularly as I knew I had not knowingly done anything that could have exposed myself to infection. I have since discovered that I was given contaminated factor VIII on 12 May 1981 at the Haemophilia Centre at the Royal Free Hospital when I attended due to one of my nosebleeds and Professor Kernoff was in charge of my care. I have found a record dated 12 May 1981 confirming that I was to commence concentrate and that blood samples were to be sent for HBsAG (surface antigen of the hepatitis B virus) screening (WITN1000008).
19. Within my medical records I found a copy of a letter from Dr GRO-D Senior Registrar at the Royal Free Hospital to my GP dated 13th May 1981 (WITN1000009) which states I was administered factor VIII at home and then taken to hospital on the evening of 12 May 1981 where I was given cryoprecipitate. This is completely untrue. I was not treated at home. I was never treated at home with blood products at any point prior to 2007. I was undoubtedly given factor VIII at the Royal Free Hospital.
20. This is in fact confirmed elsewhere in my medical records. The notes recorded of my attendance on 12 May 1981 confirm I was initially given "BPL 510 HL"

when I was at the hospital and that when that did not stop my nosebleed I was given cryoprecipitate that stopped the bleeding (WITN1000010).

21. Eventually, I received a letter dated 4 March 2013 from the Royal Free Hospital that acknowledged that I was given factor VIII at the Royal Free Hospital on 12 May 1981 and apologised for what they said did "*appear to be an error*" (WITN1000011). In light of what I have discovered since I do not accept that such a basic error could have been made. There must have been a more sinister motive behind it.
22. I have since attempted to contact Dr GRO-D by email to find out why this letter was sent in the first place and if she would talk to me about my situation but she has declined to speak with me.
23. I have gone through my medical records and can find no documented reason to justify why I was given factor VIII on 12 May 1981. I was 12 years old and had previously responded well to cryoprecipitate and did so the same date I was given factor VIII and did so after that date. I now know that it was widely known by haemophilia doctors that there was a significant risk of transmitting hepatitis through exposure to pooled factor VIII concentrate. I cannot understand why the haemophilia doctors at the Royal Free Hospital would choose to recklessly expose me (or anybody else) to such a risk.
24. As I looked into this further I obtained a copy of the minutes of a meeting of the UK Haemophilia Centre Directors held in Glasgow on 30 September 1980 (WITN1000012). On page 9 paragraph 6 it refers to a discussion of "*Reports from Working Party Chairman (a) Hepatitis*". In this section it is noted:

"... First time exposure to large pooled factor VIII concentrate resulted in many cases of hepatitis, especially in von Willebrand's disease patients..."
25. These minutes of key meetings, which Professor Tuddenham from the Royal Free Hospital (see discussion regarding von Willebrand's disease on page 13 of the minutes) and other leading clinicians from hospitals across the United Kingdom attended, make it very clear that it was recognised that giving factor

VIII to previously untreated patients carried a very high risk of the transmission of hepatitis.

26. The fact that the haemophilia doctors at the Royal Free Hospital knew about this at the time I was given factor VIII on 12 May 1981 is in any event confirmed by the fact that my blood was immediately sent for HBsAG screening (WITN1000008) and as confirmed by the entry in my medical records dated 13 May 1981 I was required to have "LFT's weekly for 6 weeks" (WITN1000010).

27. In another letter from the Haemophilia Centre to my GP dated 30 September 1982 (WITN1000013), it states that I had episodes of epistaxis (nosebleed) that responded to infusions of cryoprecipitate. It then goes on to state:

"His aspartate transaminase is once again elevated at 156 although an alkaline phosphatase of 576 may be normal for a growing child. His AST was also elevated in August 1982 – 6 weeks after receiving intermediate factor VIII concentrate and he may have a persistent non-A non-B hepatitis..."

28. It is now apparent that the reference to August 1982 is an error and it should read August 1981 as this corresponds with a record of elevated AST of 154 from serum dated 14 August 1981 in a document that stated that I was a "Natural clearer" of HCV that is dated 18 January 2007 and refers to Professor Lee (WITN1000014). The period between 12 May 1981 and 14 August 1981 therefore provided an incubation period of 94 days, although I was fortunately asymptomatic.

29. In an unaddressed letter from Dr [GRO-D] dated 2 February 2007 (WITN1000015), Dr [GRO-D] states that my stored samples from 2 June 1992 and 25 November 1994 were retested in October 1998 as part of a study of natural clearers and came back negative. I did not knowingly participate in any such study and never consented for my blood to be used for such purposes. I have trawled through my available medical records on a number of occasions but cannot find any reports showing such results. I would like an explanation as to why I was never told that I had been infected with HCV, why I was used in the study and to see the reports that Dr [GRO-D] was referring to.

30. Within the same letter it is also suggested that on 2 June 1992 I had a discussion with a Registrar called Paul Telfer whilst I was visiting my father and that we had a discussion about HCV testing. This is another fabrication. Whilst I may have had blood taken that day that was ultimately tested for HCV, I had no knowledge or concerns about HCV or that I was being tested for HCV until I read through my medical records in November 2006. I certainly was not told about the results, as had I been told I would have demanded further tests at the time.

31. In a letter from Professor Christine Lee to my GP dated 12 November 2004, which discusses concerns regarding vCJD (WITN1000016), Professor Lee also states in relation to me:

"... His question was of who to blame and he was also concerned about hepatitis C."

32. I have found the relevant entry concerning the appointment on 12 November 2004 in my medical records, which also states that I was "*concerned about HCV – per neg 25.11.02*" (WITN1000017). I vividly recall the appointment in question, particularly the discussion with regards to vCJD, which was a significant concern at the time. I categorically deny Professor Lee's assertion that I mentioned anything about HCV as at that time I was not aware I was being tested for HCV and it was something that I had never thought about. Why would I wait until November 2004 to raise concerns about the results of tests that were undertaken in November 2002? This makes no sense.

33. It is also remarkable that Professor Lee makes no reference to the study of natural clearers referred to by Dr GRO-D in her letter dated 2 February 2007 or indeed the alleged retesting that Dr GRO-D claimed to have occurred in 1998 (WITN1000015). If I had tested negative and it had been concluded that I was a natural clearer in 1998 then why was I not told and why is there no record of this in my medical records?

34. In March 2008 I wrote to the Royal Free Hospital to complain and seek answers as to how this had all been allowed to happen to me. I received a response dated 29 May 2008 from Professor Edward Tuddenham, who remained Director

of the Haemophilia Centre, which contained a number of inaccuracies (WITN1000018). I found Professor Tuddenham's response to the third question, which effectively asked who it was that had concluded I was a natural clearer and why particularly troubling:

"... The responsible clinicians for your case were Dr. Peter Kernoff (now deceased) and Dr. Christine Lee (retired). If anything was said to you about it I assume it was by one of those two."

35. In this letter I feel that Professor Tuddenham has failed to take any responsibility for my situation or acknowledge any personal knowledge of what was going on. Upon reading the content of this letter it would appear that Professor Tuddenham was not involved in my care and was simply reviewing my records. Again this is incorrect. I attach a copy of both an entry dated 22nd May 1981 that corresponds with a "drugs to take home" sheet at the bottom of a pile of such sheets (WITN1000019) that make it very clear that Professor Tuddenham was personally involved in my care in May 1981.
36. This was further compounded by the content of a further letter that I received from Professor Tuddenham dated 13 June 2008 (WITN1000020). In it, Professor Tuddenham untruthfully states the following:

"... Necessarily my opinions are based on written records and discussions with colleagues but I have done my best to understand what went on here before my time."
37. Professor Tuddenham had in fact successfully treated me with cryoprecipitate on 26 November 1980, which was the last time I needed any blood products prior to being infected on 12 May 1981 (WITN1000010). Alongside Professor Kernoff he was the Co-Director of the Haemophilia Centre so must have been aware of what was going on there when I was infected.
38. Perhaps most troublingly as far as Professor Tuddenham's personal knowledge of my particular care and treatment is an entry in my medical records from June 1981 (WITN1000021). On that occasion I had attended the Royal Free Hospital after injuring my left shoulder in an accident at school and it was suspected that

I had a rotator cuff bleed. The note of this attendance confirms that the treating doctor saw me with Dr Tuddenham and the next note states "for BPL n700v". To this day I do not know if I was given another dose of factor VIII that day.

39. I am also puzzled by the fact that in my private communications with the Royal Free London NHS Foundation Trust I am told that in response to the concerns I had raised, Professor Tuddenham had asserted that he and his colleagues were not aware that they were deliberately giving products that they knew to be more dangerous than other products. The position is confirmed in a letter I received from Stephen Evans, Head of Complaints and PALS to me dated 4 April 2013 (WITN1000022, yet in an interview with the Hampstead Highgate Express (WITN1000023) published on 5 October 2016 under a headline titled "*Medics knew risk of HIV-infected blood given to patients at Royal Free Hospital*" Professor Tuddenham admitted he knew blood products given to patients were infected with the deadly HIV virus. Further, Professor Tuddenham is quoted as saying it was not a "*policy issue*" to tell every Royal Free patient that switching to other treatments would reduce the dangers of catching the deadly viruses. How could they not tell us?
40. The more I read and discovered, the more I suspected that the clinicians at the Royal Free Hospital knew of the risk in relation to the blood products that they were administering to patients and that they had carried on regardless. I have tried to get answers from these clinicians as to why this has happened and have been repeatedly fobbed off despite there being considerable evidence.
41. I researched matters further and located some published academic papers on blood products and blood borne viruses. I found a paper that had been published in the British Journal of Haematology in 1985 titled "*High risk of non-A non-B hepatitis after a first exposure to volunteer or commercial clotting factor concentrates: effects of prophylactic immune serum globulin*" (WITN1000024).
42. The paper's authors include Professor Peter Kernoff, Dr Howard Thomas and Professor Christine Lee and it was based upon research carried out at the Haemophilia Centre and Haemostasis Unit at the Royal Free Hospital between April 1978 and March 1983.

43. I was shocked to read the reasoning and methodology behind the research, which stated that:

"Since 1978, both because of increasing awareness of the probability of underdiagnosis of acute post-infusion hepatitis, and because we wished to obtain plasma samples which might be used as sources of antigen/antibody in assays for serological markers of NANB infection (Luo et al, 1983), we have prospectively monitored biochemical liver function tests in patients receiving first exposures to clotting factor concentrates and cryoprecipitate whether or not they had previously received other blood products. The very high incidence of acute NANB hepatitis observed following concentrate therapy prompted a pilot clinical study of prophylactic immune serum globulin (ISG)...

Blood samples were taken, and patients clinically assessed, immediately before their first exposure infusions, at 1-2 weekly intervals for the next 3 months, and at 1-2 monthly intervals for a further 6 months. Biochemical liver function tests were carried out on all blood samples, and were normal in all patients before first exposure infusions. Sera were stored frozen and selected samples from all patients retrospectively analysed for serological evidence of acute or previous viral infection...

The occurrence of acute post-infusion hepatitis was the primary endpoint of the study."

44. I could not believe what I was reading. I was infected with HCV on 12th May 1981, which was during the second half of this study. Professor Kernoff, who was the Consultant in charge of my care when I was infected, had led the research and was clearly acutely aware of the probability of infection. Despite this, I was given factor VIII in circumstances where I never had the chance to reject it and avoid HCV infection. I believe that I was deliberately infected so that they could use me as a guinea pig in this study and other research on PUPs that was being carried out at the Haemophilia Centre and Haemostasis Unit at the Royal Free Hospital.

45. In a separate article written for the Forum on AIDS, hepatitis and hemophilia in 2004 (WITN1000025), Professor Lee stated as follows:

"In 1982 I was funded by the charity Action Research to research non-A non-B (NANB) hepatitis in hemophilia. Peter Kernoff and Howard Thomas were my supervisors and I was to follow patients after their first exposure to large pool clotting factor concentrates – so-called 'virgin' patients. It was only later that North Americans used the term PUPs (previously untreated patients)."

46. Professor Lee has since admitted during the course of a recorded interview with The Royal College of Physicians' Oral History Project that they were routinely storing patients' blood without permission and to testing these samples for HIV and HCV without consent. She also confirmed that it was those patients with less severe conditions who were being investigated and that testing liver enzymes every two weeks during the first three months after being given an infusion was crucial for detecting Non-A Non-B hepatitis infection.
47. I have been unable to find any other reasonable explanation for the decision to give me factor VIII. Other treatment for acute bleeding in von Willebrand's patients was effective and available, which included not only cryoprecipitate but by that point also DDAVP. There was absolutely no good reason for me to be given factor VIII in May 1981.
48. On page 474 of the same research paper there is a table documenting patient characteristics, treatment and outcomes in prospectively studied patients. I strongly believe that Patient 19 is my deceased brother Angus. Patient 19 was 15 years old when they were first given NHS Factor VIII, their HCV incubation period was 50 days and they were symptomatic. According to his medical records (which I have been given access to but are controlled by his widow Annette Hill-Stewart) Angus was first given factor VIII (HL2706) and exposed to HCV on 1 December 1980 when he was 15 years old and an entry dated 27 February 1981 in his medical records confirms that his AST levels were first recorded as abnormal when checked on 20 January 1981, which was 50 days

after he was first given factor VIII. As with my infection, this had all occurred whilst Angus was under the care of Professor Kernoff.

49. I have also seen a letter from Professor Kernoff to our GP dated 4 March 1981, which concerns my brother Angus. It confirms that Angus had *"...had an attack of acute hepatitis in late January of this year which was attributed to a transfusion of factor VIII concentrate given on 1.12.80..."* and that *"... At present, we attribute his attack of hepatitis to a non-A non-B virus infection..."*. He was therefore clearly symptomatic. Despite this, as far as I am aware our parents were never informed of what Angus was actually suffering from by the doctors and to the best of my knowledge Angus did not discover he had HCV until much later in his life. They gave him a death sentence and chose to keep it from him, thereby preventing him from seeking earlier treatment and the chance to live a longer, healthier life.
50. I do also have concerns that I may well have been Patient 11 in this research study. Although I was 12 years old when I was given factor VIII on 12 May 1981 and Patient 11 is recorded as being 13 years old at the time they were first given factor VIII, given the mistake made in the letter from the Haemophilia Centre to my GP dated 30 September 1982 (WITN1000013) that wrongly refers to August 1982 as opposed to August 1981, it may well be that the incorrect age has been input in the table. Like me, Patient 11 had an incubation period of 94 days and was asymptomatic.
51. When looking through Angus' medical records I also discovered a document titled *'Hepatitis Survey Form C1'*, which was dated 18 February 1981. Whilst that document neatly summarises everything that was by that point already known by the doctors about Angus being infected with hepatitis as a result of being given factor VIII on 1 December 1980, there is also a record of an assessment of potential other sources of contact with hepatitis within the previous six months. I was again shocked to read that it was recorded that Angus had had contact with non-A non-B hepatitis and that this had been through having contact with our father.

52. Whilst I was aware that my father had died as a result of HCV and liver cancer, I had no idea when he had been infected or when it was known that he was infected with HCV. I obtained a copy of my father's medical records and found the same '*Hepatitis Survey Form C1*' completed by Professor Kernoff dated 15 April 1980 (WITN1000026). It confirms that he was given concentrate for the first time on 11 January 1980 and had developed hepatitis by 17 March 1980.
53. I also found a '*Hepatitis Survey Form C2*' which states that between 11 January and 4 March 1980 my father was given factor VIII batch numbers HL2644, HL2651 and HL2654 (WITN1000027). At the bottom of the page it reads "*Non A non B hepatitis attributed to HL2644*". Just like Angus Junior and I, my father was therefore infected with HCV as a result of the very first batch of factor VIII that he was given at the Royal Free Hospital. Further records confirm that at the time he was given HL2644 on 11 January 1980 the consultants with overall charge of his care were Professor Kernoff and Professor Tuddenham (WITN1000028).
54. Within my father's records there is also evidence confirming that his blood was being taken and stored for the purpose of research. An entry dated 23 December 1980 states "*Extra for* GRO-D" and another dated 16 March 1981 states "*Store serum (Dr* GRO-D*)*" (WITN1000029).
55. I never knew that my father had HCV before he died and I did not realise that his liver cancer had been caused by his infection. To the best of my knowledge my father was never told about it either. There is a letter from Professor Christine Lee to our GP dated 12 March 1991 (WITN1000030). Within the letter Professor Lee apologises that "*... we seem not to have communicated to you for some years...*" and when addressing each of my father's health conditions leaves his "*chronic hepatitis*" until last as if it was an afterthought.
56. Based upon this letter from Professor Lee and my own personal recollection I believe the fact that my father was infected with HCV was suppressed by the Haemophilia Centre at the Royal Free Hospital until it got so bad that it could not be ignored any longer and our GP was then told but even then they did not bother to tell my father about it or how serious it was. As a result of this, I now

know that HCV wreaked havoc in my father's body over the course of at least a decade and ultimately resulted in him developing liver cancer and suffering a death that he did not deserve.

57. What I have discovered about what happened to me, my brother and father at the Royal Free Hospital angers me to this day, but beyond being infected, the fact that we were not immediately told about our HCV infection by any of those we trusted to take care of us and act in our best interests is one of the most difficult things to accept.
58. Having carefully considered all of the above, I believe that the clinicians at the Royal Free Hospital not only knew of the risks in relation to factor VIII from at least 1978, they nevertheless continued to administer it to patients, including me, my brother and my father. I believe this was carried out systematically. I further believe they knew that patients under their care had been infected with HCV but chose not to inform patients until they felt they had no option but to do so. I have tried to get answers from these clinicians as to why this has happened and have been repeatedly fobbed off despite there being considerable evidence to support these beliefs.

Other Infections

59. In addition to being infected with HCV, due to being given blood products between 1980 and 2001 I was also exposed to vCJD. I knew nothing about this until I received a letter from the Haemophilia Centre at the Royal Free Hospital dated 20th September 2004 notifying me that I fell into the group of 'at risk' patients and that I could find out if I had received an implicated batch if I wanted to.
60. Although I was terrified by the prospect of having vCJD I immediately decided I had to find out if I had received an implicated batch and sent back a letter in reply dated 21 September 2004. I was then invited to an appointment with Professor Christine Lee at the Haemophilia Centre at the Royal Free Hospital on 12 November 2004. I was told that I had not received any known implicated batches but I would remain on the list of 'at risk' patients for the rest of my life as the possibility of infection could not be ruled out. I was very distressed by

what I was being told and could not understand how it could have been allowed to happen.

61. I also wish to highlight a letter I have since found from Professor Christine Lee dated 12 November 2004, which refers to my daughter Tiffany and vCJD (WITN1000031). Professor Lee states that she saw Tiffany that day i.e. at the same time as my appointment with her about my vCJD status. The contents of this letter are simply untrue and represent a further fabrication of events at the Royal Free Hospital. Tiffany was then 10 years old and was not seen at all at any time in relation to vCJD. I am very clear about this as given the uncertainty we did not want to worry her unnecessarily but the hospital staff were of the view that she should be told. They eventually agreed not to tell her until she was 18.
62. The fact that the contents of the letter dated 12 November 2004 are untrue is further confirmed by a subsequent letter dated 7 April 2010 from Professor Tuddenham advising that Tiffany was in fact not at risk of vCJD, and had been declassified (WITN1000032). At the end of the letter Professor Tuddenham admits that Francesca and I were right about never telling Tiffany about it and not having worried her unnecessarily.
63. It is difficult to accept that this has happened to me and that through no fault of my own I am treated differently due to the special precautions that are taken whenever I go to the dentist or receive medical treatment due to my HCV and vCJD status. I have had several operations cancelled after being put at the back of the surgery list due to my vCJD status, which included one operation on my spine to correct a prolapsed disc. As a result I had to wait a further month for surgery and was in constant agony during that period, which I feel was completely avoidable.
64. To this day, the thought of developing vCJD horrifies me and this undoubtedly exacerbates the psychological effects of discovering that I was infected with HCV that I have had to live through. It is difficult to explain how these feelings take over but once I am in the grip of these thoughts and feelings it is difficult to escape.

Consent

65. As far as I am aware, when I attended the Royal Free Hospital on 12 May 1981 the treatment options were not discussed. It was simply a case of my parents trusting the doctors to treat me properly and they wrongly assumed that what I was being given by the doctors was safe. In the circumstances, whilst my parents must have consented for me to be treated due to the fact they had taken me to the Royal Free Hospital and placed me in the care of the doctors in the first place, the consent that they gave was not informed and was therefore invalid such that the treatment carried out on me was unlawful.
66. Had my parents been told about the high risk of me being infected with hepatitis as a result of being given factor VIII and had the alternative options properly explained to them, I am certain that they would have stopped the doctors from giving it to me and insisted that I be treated as I had been previously (i.e. with cryoprecipitate) or by other safe means that were available at the time (such as DDAVP).
67. In any event I know that there was no consent given for me to be one of the test subjects in the clinical/academic research on PUPs pursued by the haemophilia doctors at the Royal Free Hospital. Neither my parents nor I ever consented to having my blood taken, tested and stored for the purposes of research on HCV and we were never told what was happening. I am also now aware that I was repeatedly tested for HIV without my knowledge or consent. The doctors would say they were just checking my levels and I thought that giving regular blood samples was purely to do with monitoring my von Willebrand's. I feel that my parents and I were completely misled about what was going on and put simply we were deliberately lied to in order to facilitate my unwitting participation in illegal clinical research.
68. In addition to the above, I never gave my consent to participate in the alleged 'study of natural clearers' that was evidently being conducted by the haemophilia doctors at the Royal Free Hospital including Professor Christine Lee and Dr GRO-D I was never told that such research was being carried out or about the reported results. Had my consent been sought I would

have discovered that I had HCV many years earlier than I did and things may well have been very different today.

69. I cannot understand how as recently as the 1990's and 2000's doctors felt able or were allowed to get away with carrying out research on patients without their consent and believe that the conduct of these doctors should now be fully investigated and those who knowingly participated in this research and/or covered up that it was happening should be the subject of criminal prosecutions.

Impact

70. I feel it is important to point out that up until the shock of discovering I had HCV in 2007 and notwithstanding my von Willebrand's disease, I felt fit and healthy and was a very active person. I did experience some fatigue and a feeling of a lack of energy at times but I thought that this was natural. I had a great relationship with my partner Francesca and our three beautiful children and we were all very happy living together as a family (WITN1000033).
71. However, after learning that I was infected with HCV my life changed beyond all recognition. I went from leading a full, active and happy life, enjoying work and spending lots of time with my friends and family to finding myself depressed, sitting around not being able to function and not up to working. This ultimately resulted in me moving out of the family home and separating from Francesca.
72. Up to 2007 I had worked consistently and full-time throughout my adult life. When I found out I had HCV I was with a company called EMCOR whom I had worked for a period of some 10 years. I was a trusted employee and my career had progressed to a stage where I had earned almost £80,000.00 during the 2006/07 tax year. I enjoyed my work immensely and also really enjoyed spending time with my work colleagues both inside and outside of work.
73. I began dating Francesca when I was 19 or 20 years old. Francesca and I have since had three children: Tiffany who was born in 1992 who also has van Willebrand's disease, Jade who was born in [GRO-C] 1994 who does not and Alfe who was born in [GRO-C] 1999 [GRO-C]
[GRO-C]

74. Whilst Francesca and I never married, we did get engaged whilst we were on holiday in the Bahamas in 2001 and we intended to get married in our own time when we felt ready and able. We had a strong relationship and whilst we would have some minor arguments as normal couples do, we never had any break ups or periods of separation. Prior to finding out about my HCV we were a very happy family and generally life was good. I was able to work and Francesca was able to look after the children.
75. Financially things were good and Francesca did not have to work such that she was able to enjoy looking after the children. I was proud of the fact that I was rewarded for working hard so that I was able to look after my family well, which included taking them on holidays and spending quality time together. In 2005-2006 I was able to take the family to Disneyworld and we had previously enjoyed holidays in the Caribbean. We had a Land Rover Discovery and we would often make trips to Clacton as a family where we had a static caravan by the beach. I recall feeling very happy and would go as far as to say I was very lucky to have been living such a good life with those that I love.
76. Everything changed on the day that I was told that I had HCV. I attended an outpatient appointment at the Haemophilia Centre where I was seen by Dr Barbara Sibble and Dr Chowdary. I recall it was Dr Chowdary who confirmed the results of the tests, which showed that I was positive for HCV. Francesca was at the appointment with me. Both she and I were extremely shocked by the diagnosis. I remember feeling really angry and asking them several times how it could have happened and who was responsible. I could not understand how this could have happened to me and struggled to cope.
77. Whilst I knew that it was something very serious, I did not fully understand the precise health implications or treatment options. I do not feel that the information and advice that I was given by the doctors was sufficient and it certainly did not address what HCV could have done to my body since 12 May 1981 or my concerns that as a result of HCV I would soon be 'a goner' like my father.

78. Over the course of the next few weeks I began to look into things and became very, very distressed by the information I was finding out. I could not believe the doctors and nurses who had been looking after me from childhood could have been so careless or reckless with my life. I felt really badly let down by all of them and began to question the treatment that my brother Angus and our late father had received from them. I began researching to try and understand what had happened to me and to them.
79. The quest for answers admittedly took over my life and became overwhelming for me as I developed progressively severe depression. After starting treatment in February 2007 I was off work sick from May 2007 until about April 2008 and then returned on light duties from around May 2008 until August 2009 when I stopped working due to my mental ill health. Despite my best efforts I simply could not "get myself together", go back to work properly or resume life in any sort of normal way at all. I felt as though I was having some sort of "breakdown".
80. During this period I felt as though I simply could not function in any normal way and as I could see the impact this was having on Francesca and our children I started to feel really guilty, which made me even more depressed. This was made worse when I started treatment. On reflection I behaved very badly in that I was very bad-tempered and snapped a lot at Francesca and the children. In August 2009 I moved out of our home and went to stay with my mother.
81. When I moved out, Francesca was left to do everything and as I was no longer working she was forced to take a job as a dinner lady at a local school so as to make ends meet. I feel very guilty and embarrassed about what happened, particularly the way I behaved towards Francesca and the children during this period of time. In the months and years that followed I desperately wanted to get my old life back but could not see how to do it.
82. I was also soon aware that I was placing additional strain on my mother with the additional work she has had to do to take care of me. My mother continues to be very supportive but I do worry about her as she is getting on a bit and her own health is not good.

83. Since the onset of my diagnosis and changes in my mental health, I have tried to engage as fully as I can in all the support offered to me over the years. I have always been as honest and open as possible when attending the very many counselling sessions that I have undergone. I have engaged in CBT and attended recovery centres on multiple occasions but never felt that I was understood or that anybody believed what I was telling them.
84. A prime example of this occurred in April 2015 when I was discharged from Camden and Islington Mental Health Services after years of therapy with a diagnosis of "Depression and Delusional disorder". In a letter to my GP from Dr [GRO-D] the Clinical Psychologist at Camden and Islington NHS Foundation Trust dated 18 April 2015 (WITN1000034) Dr [GRO-D] says this about me:
- "... now he has a choice about whether to keep fighting for the contaminated blood cause, or to try and think about the things in life that are important to him and rebuild a life worth living."*
85. I was and regularly continue to be extremely depressed, however, I am not and have never been delusional. I am glad that I never took the easy option and did not give up on this 'cause'. Dr [GRO-D]'s opinion and comments about me are upsetting and I would say it has been very easy for people like Dr [GRO-D] to form such quick judgments about me when they were not fully aware of the facts, particularly as the extent of the contaminated blood scandal was suppressed for so many years.
86. I continue to mentally struggle on a daily basis and have not been able to move beyond my feelings of anger, betrayal and utter despair that I have felt since I found out and continue to feel today.
87. I have been forced to live in fear of what HCV has done to my body since 12 May 1981 and may be doing now, particularly to my liver. I know that I could develop liver cancer at any time and I am acutely aware of what I would have to face if this were to happen having had to live through the nightmare of what both my father and brother had to go through before their untimely deaths. I worry about what this would do to my family, particularly the impact it would have on Francesca and our children.

88. I am not half the man that I was prior to January 2007. I am still on daily medication, which includes antidepressants, mood stabilisers and sleeping tablets. I want to get my old life back properly but often struggle to see any way forward. I still feel extremely depressed and angry and at times suicidal. I can only describe it as demons going round and round in my head tormenting me about what has happened that will not go away. I have often found myself praying that I do not wake up in the morning.
89. It is only the thought of Francesca and our children that kept me from going completely into the abyss. Despite our separation, I am fortunate that Francesca has continued to support me and has been able to see that I am not delusional and there has genuinely been something terrible happened to me. I can only hope that with time we may be able to work towards rebuilding our relationship and enjoying our beautiful family together.
90. I was fortunately able to return to work in September 2016 working as a Logistics Manager initially in Cambridge and now in Holborn in London but I am not working at the same level or with the same enjoyment that I was before. I generally work between three and five days a week, but it may be less depending on my mental health. My employer and colleagues are extraordinarily understanding of my circumstances. I have some really bad days when I struggle, and therefore cannot work, but other days are not so bad and I do my best to go to work on those days.
91. To this day I still find myself in very dark places mentally and suffer strong feelings of not wanting to be here. When things get too much or really bad I now call the crisis team or if it is out of hours attend A&E. I will be admitted to the recovery centre, typically for 3 or 4 days at a time but then will have to go back on a daily basis for 3 months. I am very scared at the thought that I might end up being sectioned during one of these periods.
92. I still cannot believe how badly the doctors at the Royal Free Hospital treated me over so many years. They infected me with HCV and did not give me a chance to avoid it or deal with it. I understand that even if I had been told about my HCV infection and treated earlier, it might not have cured it but had I known

sooner I feel I would have been able to come to terms with what has happened, adjust and plan my life accordingly. I have completely lost all trust and faith in the doctors who I thought were looking after me all those years. I feel as though my whole life has been devastated.

Treatment/Care/Support

93. After I found out that I had HCV I was started on a combination of Interferon and Ribavirin, which was aimed at clearing the virus from my body. I remember the first time I injected this treatment as I was at home on a Friday night and within 20 minutes I felt terribly sick and completely wiped out. After each treatment I suffered for three or four days with terrible flu like symptoms including nausea, fevers and an aching body. In addition I lost a lot of weight, suffered with hair loss and most significantly I suffered from two detached retinas, which caused me to fear losing my sight and necessitated corrective surgery at Moorfields Eye Hospital.
94. The Interferon and Ribavirin was supposed to last for 24 weeks, however when I was about 6 to 8 weeks into the treatment Dr GRO-D suggested that I should stay on the treatment for an extra 24 weeks, an approach that was endorsed by my Consultant Hepatologist Professor Geoff Dusheiko. I therefore underwent this treatment for a period of 48 weeks in total. I was told that this would give me a better chance of a cure and I believed them, particularly as my brother Angus had relapsed a couple of months prior after having had treatment with Interferon and Ribavirin for 24 weeks.
95. I agreed to the extended 48 weeks of treatment as I understood it was necessary. However, when I got to week 24 I was told that Camden PCT were not going to fund the extra 24 weeks of treatment that I needed and that I would have to pay for it myself at a cost of approximately £7,000.00. I was extremely shocked by this and efforts were made on my behalf to persuade Camden PCT to change their mind but to no avail (WITN1000035). Finding the £7,000.00 to fund the treatment was no easy feat for me at the time, particularly as by that point I was unable to work and only receiving statutory sick pay. However I did manage to raise the funds and paid for the treatment as I believed it was something that I really needed.

96. I complained to the Healthcare Commission about this and after some months I understand the Healthcare Commission made recommendations to Camden PCT in respect of my case. I subsequently received a cheque for the sum of £2,800.00 by way of a partial refund. I was told that this was a "goodwill gesture", which I found insulting.
97. I subsequently researched the NICE guidelines and the evidence for treatment of the type of hepatitis that I had (HCV genotype 3) and it seems that I should not have been advised to have this extended course of treatment in the first place as there is no clinical evidence suggesting a better chance of a cure. The NICE guidelines categorically state that people with HCV genotype 3 should be treated for a period of 24 weeks.
98. I have therefore effectively had to pay the Royal Free Hospital £4,200.00 for something that was not only not going to help me but which also put me through an extra 24 weeks of severe and debilitating side effects for nothing. The treatment with Interferon and Ribavirin is brutal and the fact that I was led to believe that I required an extra 24 weeks of this for no valid reason whilst charging me for the privilege still fills me with dismay whenever I think back on that period.
99. I took approximately 11 months off work from around May 2007 until April 2008 whilst I underwent treatment. I was keen to get back to work as soon as possible and returned in May but I felt like I was having some sort of "breakdown" and was unable to cope so stopped working in August 2009. I only returned to work in September/October 2016.
100. Unfortunately the treatment did not work. I was desperate to try and get rid of the HCV and therefore in 2010 I agreed to go on a trial at University College Hospital in London. This involved 24 weeks of not only Interferon and Ribavirin but also another drug, the name of which I am not able to remember and have not been able to find out from my records. Unfortunately this did not work either.
101. In 2013 I agreed to take part in a further clinical trial, this time at the Royal Free Hospital. Much to my dismay this did not work either.

102. Then in 2014 I was offered the chance to take part in a clinical trial of treatment with Sofosbuvir in combination with Ribavirin for a period of 6 months at the Royal Free Hospital. I agreed to take part and had to go to the hospital every week to be blood tested. By the end of the trial the blood test results came back to state that the HCV was undetectable. I do not know whether I have permanently cleared the virus and have not undergone any recent testing for fear of finding out that it has returned.
103. I believe that all the HCV treatment I have endured has had a significant long-term effect on my physical capabilities and when I compare myself to healthy people of a similar age I know that physically I cannot do what they can do, whereas I used to be able to before all of this happened.
104. Due to the psychological effect of discovering I was infected with HCV and the circumstances of my infection, I have been repeatedly referred to psychological support services, which included the Camden and Islington NHS Complex Depression, Anxiety and Trauma Team ('CDAT'), and have received various counselling and other psychological therapies over the years. I have had 20 sessions of counselling that were funded by the Caxton Foundation, paid for additional private counselling, received 15 sessions of CBT and attended mindfulness groups at the Recovery Centre in Tavistock Square.
105. Despite all this I continue to struggle on a daily basis and have not been able to move beyond my feelings of anger, betrayal and utter despair that I have felt since I found out and continue to feel today.
106. I am desperate to get better and to move forward from this, but so far no kind of psychological support has had any real beneficial effect. Being labelled "*delusional*" particularly put me off. If anything, being treated by people who did not believe what has happened to me made things worse. I felt if nobody would believe me how could they possibly help me?
107. As a result, at the moment I have decided not to continue with counselling but I am still under the care of my GP and currently take Zopiclone to help me sleep, Citalopram for my depression and Olanzapine to stabilise my mood on a daily

basis. I have been taking this medication for a long time and it appears that I will need to carry on taking it for the foreseeable future.

108. Aside from the above, I am lucky to have Francesca, our children and my mother in my life, who continue to provide love and support despite everything that has happened and the changes they have witnessed in me.

Financial Assistance

109. After discovering I had been infected with HCV I received two payments from the Skipton Fund. I received an initial Stage 1 payment of £20,000.00 and then received a further £30,000.00 some time later. I am now receiving £18,000.00 per year from EIBSS, which is paid on a monthly basis.
110. I also received some funding from the Caxton Foundation for counselling sessions and the odd household necessity but it was never made available without a struggle.
111. I feel great embarrassment at being in a position where I have been forced to rely on such handouts but also feel that the application processes and the people managing the funds have not helped this feeling of shame. It always felt like unless you could show you were in poverty they would not give you anything.
112. I have been forced to accept this money on the basis that I am ill and struggle to work so the funds are obviously of some help. However, I do not feel at all happy about it and it feels as though I and all the others infected and affected have been paid off and continue to be paid off in a very cheap and underhand way.
113. In addition to the funding schemes, in around July 2008 I instructed solicitors to pursue a claim against the Royal Free Hospital NHS Trust for clinical negligence. At the time the true circumstances of my HCV infection were not known such that it was believed that I had been an unfortunate recipient of contaminated blood and it could not have been avoided. My solicitors sought the expert opinion of Dr Mervyn Davies and it was concluded that it would likely be found that it had been reasonable to give me factor VIII in May 1981 such

that there were not reasonable prospects of successfully establishing any negligence or wrongdoing in respect of my HCV infection. My claim was therefore brought on the basis of a negligent delay in diagnosis and treatment of my HCV and the circumstances of my original infection were never considered as an issue in the proceedings.

114. In January 2013 my claim for damages was eventually settled without an admission of liability for the net sum of £80,000.00 just a few weeks before Trial following a round table meeting. Although this was less than what I had been told the claim was potentially worth, I accepted this settlement as at the time I was advised that if I did not the Trust intended to defend my claim to trial and there was a significant risk that I would lose the case. I now feel that the Trust bought my claim off and were thereby able to avoid any formal findings being made into what had happened.

Other Issues

115. My life has been devastated as a consequence of discovering that I had been given contaminated factor VIII and everything that has flowed thereafter. I am angry about the way in which my own life has been ruined but even more so about the effects it has had and continues to have on my family.
116. Despite the battles I have faced for recognition of what I have been saying for many years and the impact of being labelled 'delusional', I remain committed to securing justice for my father and brother. They were murdered. There is no other word or label I can think of to describe what happened to them. I live in fear of suffering the same fate and often feel it is only a matter of time before something similar happens to me. Those responsible must be brought to account and punished in the criminal courts for what they have done.
117. I remain concerned about the patient with hospital number 217068 whose blood test results were incorrectly inserted into my hospital records (WITN1000005). It seems likely to me that they were also unwittingly used in the research like I was. I would like the Inquiry to ensure that that individual is identified and contacted so as to make sure that they are aware of that they were being tested

for infection and what they may have been infected with so that they can be re-tested and treated if necessary.

118. I also want to know how and why they were they allowed to do this to us. Who knew about the research? Who sanctioned it? Who funded it? Who knew about the extent of the cover up of what happened?

119. I sincerely hope that this Inquiry will finally answer my questions about what happened, help secure justice for these atrocities and ensure that all victims whether infected or affected are able to move on from this living nightmare.

Statement of Truth

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

Signed:

GRO-C

Mark Anthony Stewart

Dated:

6th - SEPT - 2019.