

Witness Name: Annette Hill-Stewart  
Statement No.: WITN1001001  
Exhibits: WITN1001002 – WITN1001019  
Dated: 12 July 2019

## INFECTED BLOOD INQUIRY

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### WRITTEN STATEMENT OF ANNETTE HILL-STEWART

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 14 May 2019.

I, Annette Hill-Stewart, will say as follows: -

#### **Section 1: Introduction**

1. I am the widow of Angus Horatio Stewart (DOB: GRO-C1965, DOD: 28.12.2013).
2. I make this statement in connection with the care and treatment provided to my late husband in respect of the management of his Von Willebrand's disease by the Royal Free Hospital (RFH) throughout the course of his life and in response to a request by the Infected Blood Inquiry in accordance with Rule 9 of the Inquiry Rules 2006.

#### **Section 2: How Infected/Affected**

##### Background

3. Angus and I met at work during 1998, it was a friendship that turned into love. Angus was a highly accredited Horologist and I was a Sales Manager. I was aware from the outset that Angus suffered from a type of Haemophilia Von Willebrand's disease prior to entering into a relationship with him. Angus was very healthy and active. He was a

tall and very 'solid' looking man. As far as I was concerned the fact that he had Von Willebrand's disease was not a major health issue. My understanding was that it was essentially a bleeding disorder and that it was sufficiently well managed so as not to have any real impact on his day-to-day life or activities. Angus also told me that he had contracted Hepatitis C from having been given infected blood products. I now know from having seen his medical records that this is classified as Genotype 3. I cannot recall exactly when this was but do remember Angus often saying that the hospital knew that he had Hep C in and around 1981 but they had kept this from him. This was a source of some considerable distress to Angus. I do not know for sure when Angus first found out that he had Hepatitis C but I have seen a letter to Angus from Dr Christine Lee, Consultant Haematologist at the Royal Free Hospital ('RFH'), informing Angus that he had Hepatitis C. The date of the letter is very unclear but looks like 9 July 1990. A copy of the letter is attached labelled WITN1001002.

4. Angus and I were married in 2001. We sold my apartment and bought a house in 2002 so his children (from his previous relationship) could stay over with us. We were really happy and led a very full and happy life. We both had good jobs and great future career prospects. Angus was working as a Senior Technical Advisor at Marks and Spencer (M&S) with a role that gave him great responsibility and international travel. From a health point of view Angus was fit and well. Over periods of time Angus would have nose bleeds and would need to have the blood vessels cauterised. Apart from this Angus did not experience any other problems. Occasionally he would feel unwell and tired with a loss of appetite. Our understanding was that this was due to flare ups of Hepatitis C.
5. I understand that Angus's condition was initially treated at Great Ormond Street Hospital and he was then transferred to the Haemophilia Centre at the RFH in 1978.

6. Since Angus's death I have obtained and reviewed Angus' medical records. I have managed to find out the following: Angus Von Willebrand's disease is described alternately as "mild" and "moderate". On transfer to the Royal Free Hospital Angus was placed under the care of Dr P B A Kernoff MD MRCP Consultant Haematologist. Angus experienced recurrent nosebleeds as a child and was initially treated in January 1980 with cryoprecipitate (cryo).
7. He had repeat episodes of nosebleeds in May and September 1980 which again was treated, it appears, successfully with cryoprecipitate.
8. On 28 November 1980 it appears that Angus attended again for a nosebleed which apparently had persisted for some 48 hours. Somewhat confusingly there appear to be two separate entries in relation to the attendance on 28 November 1980. The first states:

*"Epistaxis L for 48 hours  
Dilated vessels. Inflamed mucosa  
RX cryo 10..."*

The second clinical note in a different handwriting and a different pen also dated 28 November 1980 notes:

*"Treated today with cryo x 10 for epistaxis. Developed a moderately severe transfusion reaction – generalised erythema urticaria and rigor which was aborted with hydrocortisone...his future treatment should be changed to NHS Factor VIII concentrate – try 700u in the first instance..."*

9. On 1 December 1980 Angus attended again with another nosebleed. As far as I can tell this is when he was first given Factor VIII. Copies of the two pages of clinical notes evidencing the above are attached and labelled WITN1001003.

10. I was and remain extremely concerned by the fact that a clinical entry in Angus's records dated 11/12/81 which clearly relates to "my" Angus as the previous entry mentions school is identical to a note in Mr Stewart Senior's (Angus's Father) notes.

The note states:

*"Flare up of symptoms around 23.11.81 (anorexia. nausea. vomiting about two weeks after dose of NHS concentrate (HL2854). his first dose for eight months. Symptoms accompanied by raised AsT. which had fallen to normal by 1.12.81. Overall. this probably represents another attack of post-transfusion hepatitis. although LFTs never really normalised following his first attack in January 1981. Full blood workup in February/March 1981 was negative, and note HBsAg/ab still negative.*

*PLAN:*

*See before Christmas for review (PK) Will need repeat full blood screening including autoantibodies at that time. Probably should have LFTs checked at monthly intervals, with baseline Ba swallow and ultrasound. Although he 'doesn't like concentrate', there seems to be little alternative to carrying on with this because he has had bad reactions to cryo. Kernoff"*

Copies of both notes are attached and labelled WITN1001004.

11. I should explain that the copy of the clinical note relating to Mr Stewart Senior was provided to me by Mark Stewart, Angus's brother. As the Inquiry will be aware, Mark Stewart has also contracted Hepatitis C as a consequence of having received infected blood products.

12. Angus became unwell in February 1981. He attended hospital on 2 February 1981 where it was noted that he had been unwell for 4 days with tiredness, nausea and vomiting.

13. The clinical record (a copy of which is attached and labelled WITN1001005) notes:

*"Change to NHS concentrate in December 1980.*

*1.12.1980: HL2076*

*20.1.1981: HL2691"*

The note goes on to state:

*"Imp: acute hepatitis due to transfusion from concentrate. Could be non A or non B. Angus appears to have made a reasonable recovery with fairly mild ongoing symptoms. With occasional flare ups."*

14. According to the notes from 1982 onwards Angus was treated with desmopressin (DDAVP). This is evidenced in a data sheet attached and labelled WITN1001006.

### **Section 3: Other Infections**

15. None that we were made aware of.

#### **Section 4: Consent**

16. Angus was only 15 years of age when he was given Factor VIII. Angus told me all about his experience as a child but Angus never mentioned any kind of discussion regarding the treatment he was given on 1 December 1980 or that he was informed by the clinicians involved that the treatment he was on was going to be different to what he had been given before (cryoprecipitate).
17. My conversations with Angus's mother involved discussions about Angus's health and his Hepatitis C infection, as such she was and has been very clear about the fact that she was not informed of Angus's treatment and was definitely not warned or advised of any risks involved in being treated with the blood products.
18. I am at a loss to understand why Angus was given Factor VIII as a child when it appears that there was alternative treatment available (DDAVP) and which Angus was treated with very successfully thereafter, as evidenced in the letter from Dr Kovac to Angus's GP Dr Miller dated 24 November 1986. Copy of the same is attached and labelled as WITN1001007.

#### **Section 5: Impact**

19. During 2002 Angus's father Angus Stewart Senior, who also had Von Willebrand's disease died as a consequence of massive cancerous tumours in his liver. The cancer was confirmed to be Hepatitis C. To the best of my knowledge Mr Stewart Senior was also infected around the same time as his son Angus through infected blood products. The death of Angus's father was not only extremely distressing, but made us acutely aware of the potentially devastating consequences of Hepatitis C infection.

20. In and around 2005 Angus started to feel more and more tired and physically sick. He was also bleeding a lot more through his nose and sometimes when he went to the toilet he bled from his rectum. The RFH associated these issues with the Hepatitis C. With this in mind and the history of his father's death Angus was put on a course of Ribavirin and Interferon to treat the Hepatitis C. Although it appeared to have worked initially, it soon became clear that it had not been. Despite having gone through horrendous treatment, the virus was back. I attach a copy of the email exchanged between Angus and Dr Thynn dated 02.05.07 labelled as WITN1001008. The treatment went on for months, it made him dreadfully ill, Angus lost a lot of weight and was always grey and vomiting. Nevertheless, Angus kept on going trying to work through it, he never gave up.

21. The tiredness truly took its toll and Angus found it hard to commit to his job. He had to take time off here and there and unfortunately one of his seniors at work was most unpleasant to Angus regarding this. Angus was a proud man but he was being victimised because of his illness. We discussed this and I said I would financially support us as I had a good job while Angus started up his own business. Angus could call the shots and decide when he could work. Angus left M&S in November 2007. Soon after he left, he was inundated with people asking for support with contractual work, it seemed his business would succeed but he never got the chance to fully find out.

22. In January 2008 we went on a cruise. During this holiday Angus was quite unwell. Angus broke out in a rash, cold sores, had very swollen ankles and a sore throat. Angus went straight to the RFH when we returned and it was not long after that, Angus was diagnosed with liver cancer.

23. Although we were informed that a liver transplant was the only treatment that could save Angus's life, on the 09.04.08 a decision not to put Angus on the liver donor's list was made. The reasoning for this decision was the fact that Angus did not meet '*the Milan Criteria*'. Although I understand the need for medical policies and criteria, Angus and I were very shocked and outraged by this decision. The fact that the RFH caused Angus's disease seems not to have been taken into consideration when RFH made the decision not to give Angus every possible chance of survival. A copy of the letter from Dr James O'Brien (Consultant Hepatologist) to Angus's GP (Dr Lim) dated 09.04.05 is attached and labelled WITN1001009.
24. Angus endured a few months of embolization on the tumours, I understand that they had to freeze the tumours to slow the growth. Physically he was unwell and mentally he was breaking inside. Despite everything Angus was a very positive man. Although the RFH informed Angus that he only had a few months to live, Angus was very determined to live for as long as he could, but at this point Angus fully realised that he had been given an early death sentence.
25. During a hospital stay in May 2008 we were informed that a liver from a live donor (with a disease called amyloidosis) was available and could be transplanted into Angus in a domino transplantation procedure. It was therefore not a completely healthy liver, but for Angus it was his only hope. Angus was given his new liver on 09.05.08.
26. Initially the liver transplant was thought to be a success. However, Angus did have a lot of complications after as he was not properly stitched and suffered a major hernia. Angus had to have this surgically repaired. This involved major open surgery which was carried out in September 2010. Following the surgery Angus developed a wound infection. The infection was very serious and he walked around with an open wound and a drain for some months after.

27. Angus had to be put on immune suppressants for the rest of his life so the liver would not be rejected however, this made his immune system very weak. He was prone to viruses etc so we had to be very careful where we went and who we met. This obviously negatively impacted both his and our lives as a couple.
28. Angus was informed that the Hepatitis had cleared further to the liver transplant. A report shown to Angus showed he was negative however, when Angus looked at his medical notes while in the waiting room one day, in and around April 2010, he was very shocked to read that the Hepatitis C had returned. No one had informed him of this.
29. During a routine scan in January 2012 a growth was noted in lower lobes of Angus's left lung which was suspected to be cancerous. We were both devastated. We were advised that Angus would undergo an operation to remove the growth in his lung.
30. 7 February 2012 Angus was due to have his lung operation. However, in the morning of Angus's lung operation, whilst he was already in his hospital bed waiting to go into theatre for his operation, Angus was informed that the operation was cancelled. We were advised that the hospital's head of management made the decision to cancel the operation because Angus may have contracted Creutzfeldt Jakob Disease (CJD) through the infected blood products. The management team refused to allow the surgeon to use the operating theatre due to the risks of contamination. Fortunately, Angus had a wonderful surgeon Dr Eric Lymm, who challenged this decision, and went ahead with the operation to remove the cancerous lobe from his lung. Angus suffered severe pain post his operation and was referred to a pain nerve specialist.

31. Angus's secondary cancer affected his lung, shoulder and arm bone. Some of the tumours could be felt and seen. The tumour on his shoulder was the size of a large orange. The treatment consisted of radiotherapy, chemotherapy and later the pinning his arm. The chemotherapy and radiotherapy was brutal. Angus suffered with such severe headaches before he died, these headaches made Angus wince and cry out in pain, I am sure that the cancer had in fact gone to his brain. The pain that he endured as a consequence of the liver operation and the bone cancer was horrendous. Angus also suffered burns due to the radiotherapy as it was so invasive. Angus was given painkillers (opiates) however, these did not agree with Angus and so a lot of the time he tried to go without pain relief which was terribly distressing.
32. The fact that Angus knew he was dying before his time had a great effect on his mental state. Angus suffered on and off with eating disorders, stress and at times depression which he did his utmost to hide.
33. Physically Angus regularly suffered from chronic fatigue and was generally always tired. This affected Angus and I greatly as certain activities were limited.
34. The chemotherapy Angus was given after his lung cancer affected not only Angus's eye sight but his hands, they shook and he lost the feeling in his fingertips. As a Horologist, Angus had to have keen eye sight and steady hands. It devastated him that he could not continue to work and make a living doing something he loved to do and had devoted his adult life to learn.
35. After some disagreements with medical staff at RFH in September 2013, Angus underwent surgery to his left arm as it was at risk of amputation. The bone had almost totally eroded due to bone cancer, as a consequence Angus's arm had to be pinned to hold it together.

36. In October 2013 Angus was admitted to the RFH following a massive gastrointestinal bleed, for which he required a blood transfusion. Investigations were carried out, but the source of the bleed was not found.
37. Over the next few weeks Angus's condition deteriorated rapidly, and he was in and out of hospital.
38. Angus died on 28 December 2013 in his sleep whilst I was lying next to him, it was in the very early hours of the morning. At this point Angus was on oxygen 24 hours a day. I had dozed off to sleep for about 90 minutes, I clearly remember waking up to the sound of the oxygen machine, as it was very loud. The hallway light was on, and when I looked at Angus I could see Angus's body outline, he was so still. I gently put my hand on Angus, trying to avoid disturbing him however, when I touched Angus, he felt quite cold and at this point I realised that Angus passed away.
39. I contracted Hepatitis C from Angus before we were married. I was informed of this through the RFH when I had a blood test as I felt unwell. It was confirmed that the Hepatitis C was contracted from Angus. I was monitored and offered treatment. Fortunately, the Hepatitis C was cleared through my body naturally. We were previously told (incorrectly as it transpired) that Hepatitis C could not be transferred through sexual intercourse by Angus's doctors at the RFH.
40. Angus and I very much wanted to have a child however, after discussing this at length I decided not to. Neither of us knew what the future would hold for Angus and it would be more responsible not to. Therefore, because of the Hepatitis C infection and also the uncertainty of Angus's future life, we decided not to have any children together. Whilst this was probably a sensible decision it was totally devastating for

me as I have never had children and desperately wanted to have a child with Angus. Angus already had 3 children when we met but he did also very much want to have one with me if it was possible.

### **Section 6: Treatment/Care/Support**

41. On reviewing Angus's hospital records, (there are seven lever arch files, and I have exhibited a few as a summary of Angus's treatment and hospital visits) it appears that the records support the views which I have carried over the years. Namely that Angus was mistreated, incorrectly informed of his health and was given poor health support since the age of 15, when he was infected with Hepatitis C.
42. From the hospital records it seems that the clinicians involved failed to undertake due diligence towards the Factor VIII treatment which Angus received for his blood disorder on that fateful day during December 1980. It has to be asked: why were the blood products not screened and secondly, why did the RFH take it upon themselves to make the decision to treat Angus with Factor VIII, when he had successfully received the Cryoprecipitate treatment, in the past. To date it infuriates me to know that Angus went through this.
43. On reviewing the medical records and as a result of previous discussions with Angus's mother it is clear that nothing had been made clear to the Stewart family about the change in Angus's treatment.
44. As I have said before Angus was only a minor and was given a death sentence by the NHS department. The NHS department had a duty to ensure that Angus received if not the best treatment possible, at least treatment of an acceptable standard. I do strongly believe that the RFH gave Angus a product that they knew carried a risk of

being infected/contaminated, but nonetheless, the RFH took that risk and did so without informing Angus or his parents. I believe that Angus had been used as a human guinea pig, an experiment to test the effect of contamination with Hepatitis C.

45. When Angus required lifesaving surgery for a secondary cancerous growth in his lung, we were faced with the same battle as before; Angus was advised that given his CJD status, there was a high risk of contaminating the operating theatre, and therefore had to fight for the doctors to carry out the surgery. Angus and I were outraged, about the fact that the Trust which treated Angus with contaminated blood products, which would eventually kill him, then refused to treat him because of risk of contamination, this really added insult to injury.

46. Angus was informed he had only a few months to live due to cancerous tumours in his liver, the cause for the cancer tumours was Hepatitis C. It was and still is heart-breaking when I think about how desperate we were for a healthy liver transplant but because of a 'medical legal clause' Angus could not be put on the list.

47. Angus was required to undergo further treatment for the Hepatitis C infection, however, the RFH advised that this treatment would not be funded by the RFH, therefore this meant that Angus was required to fund this crucial treatment. The cost of this treatment was in the thousands of pounds. I still feel exceptionally angry about the fact that the RFH refused to fund the treatment, even though the RFH caused the infection by treating Angus with contaminated blood products.

48. After a long battle of trying to secure funding for the additional Hepatitis C treatment which RFH refused to fund, Angus sent an email to our local MP, Mr Grant Shapps. Angus set out his frustrations in an email he wrote on 02.10.07. Mr Grant Shapps

assisted in obtaining funding with our local PCP. A copy of which is attached and labelled WITN1001010.

49. Fortunately for Angus Mr Shapps supported Angus to receive treatment.

### **Section 7: Financial Assistance**

50. Angus received a stage 1 pay-out for £20,000 from The Skipton Fund which helped with day to day living. Angus also received a terminal pay-out of £25,000. Angus bought himself the car he always wanted and a wonderful dog called Reggie. Angus adored Reggie, and wanted to 'show' him to keep himself occupied but unfortunately due to Angus's poor health he was not able to properly show Reggie. However, Reggie's love gave Angus much happiness during his final year of life. We also went on some lovely holidays, trying to make Angus's last bit of life as memorable, loving and fun as possible.

51. I received a widow's pay-out of £10,000.

52. We also received £500 a year for winter fuel allowance.

53. As Angus had just started up his own business around the time he fell ill, he had no insurance or medical health care, nor did he have any sick pay. Given that Angus left his job voluntarily, the Department of Work & Pensions (DWP) initially refused to provide financial assistance whatsoever. I was the only one earning a salary, and therefore we were required to change the mortgage from a repayment mortgage to an interest only plan. Mentally this truly upset and embarrassed Angus, he had his pride smashed, he did not want us to tell our family.

54. Angus eventually, with the assistance of his GP, was successful in making a claim to the DWP for disability living allowance, although on two occasions the DWP threatened to stop the claim.

### **Section 8: Other Issues**

55. While looking through Angus's records I found a letter dated 14.07.94 from Hoechst Sales, Malcolm West to Dr Pasi, in which he states:

*"You will be aware of the close scrutiny that is applied to blood products and those where human blood is used in their manufacture. Haemate P has been prepared from large pools of human plasma non-reactive for hepatitis B antigen (HbsAg). However, such plasma may contain one of more causative agents of viral hepatitis. Haemate P is heated to 60 degrees centigrade for 10 hours in solution form. Nevertheless, no procedure has been shown to be totally effective in removing hepatitis ineffectively from Antihemophilic Factor (Human)*

*Haemate P is usually available in the United Kingdom after testing by the National Institute of Biological Standards and Control as required by our full product licence. Therefore any material not tested by the NIBSC cannot be covered by our product licence and is only available for use on a named patient basis. We would therefore request you sign the attached letter and return it to say that you fully understand the conditions under which we are making this particular supply of Haemate P available to you."*

Copy letter attached and labelled WITN1001011.

56. There is a letter from Dr Pasi also dated 14.07.94 in response stating that he accepts responsibility for the use of this product in his patients.

57. I am also concerned by a letter from Professor Lee to Professor Davidson dated 13.07.99. In the letter Professor Lee states "...*There are many features about his past history which are difficult to explain*". I would like to know what was so difficult to explain about Angus's medical history, that she could not explain in that letter.

58. I have also noted several references to Angus's alcohol intake. I am both shocked and distressed by this. Professor Lee suggests that Angus's disease was due to alcohol, which is untrue and insulting. Angus was a social drinker and he categorically did not drink to excess.

59. Dr Thynn Thynn Yee writes in a letter dated 12.09.07 to Angus's GP:

*"His fibro scan today revealed a quite markedly elevated value of 60.5 and this indicates cirrhosis. Under the circumstances he requires a biopsy. I specifically asked him about alcohol, he says he drinks at the most one glass of wine with dinner at the weekends. I think this certainly requires additional collaboration as previously alcohol has played quite a significant part in the progression of his live disease"*

60. I am attaching a few photos WITN1001012 to WITN1001019 to show Angus as he was when he was well, on our wedding day, and his subsequent decline as a direct consequence of him being given infected blood products and all the problems that arose from being given the infected blood products.

### **Statement of Truth**

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

Signed GRO-C

Dated 12.07.19