Witness Name: Kathleen Stewart
Statement No.: WITN1002001
Exhibits: WITN1002002 – 046
Dated: 27 September 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MRS KATHLEEN STEWART

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

I, Kathleen Stewart, will say as follows: -

Introduction

1. My name is Kathleen Stewart. My date of birth is GRO-C 1941. I currently live at GRO-C London GRO-C with my son Mark.

2. I worked for Camden Council as an escort for older people. I also worked for Meals on Wheels but had to retire from both jobs because of back and bone problems around the age of 55.

3. I am making this statement in relation to the care and treatment provided to my late husband Mr Angus Stewart (date of birth: GRO-C 1938; date of decease: 07.09.2002) received by the Royal Free Hospital in the management of his Von Willebrand's disease.

How Affected

4. Angus and I met through my sister Ellen when I was around the age of 21. We married in June 1975. We had four sons: Angus (date of birth: GRO-C 1965; date of decease: 28.12.2013), GRO-C (date of birth: GRO-C 1966), GRO-C (date of birth: GRO-C 1967) and Mark (date of birth: GRO-C 1968).

5. Between the ages of 18 – 26, Angus served in the army and was posted to Cyprus as part of the Irish Guards. This just shows how healthy Angus was, he wasn't handicapped and didn't need treatment.

6. Once he left the army, Angus worked as a cable engineer and was later promoted to manager for BT.

7. When my eldest son Angus Junior was around six weeks old, I noticed that he seemed to be suffering with a large number of nosebleeds. I therefore took him to the hospital (I believe it was St Leonard's Hospital in Hackney but am not entirely sure), but they didn't take any notice and just said I was being an overprotective mother and prescribed Angus Junior with iron tablets. When my youngest son Mark was born, I noticed that he also suffered with some nosebleeds.

8. At the time my sons were born, we were living in GRO-C but I would travel with them to see my parents in GRO-C. On one of these visits in 1969, Angus Junior collapsed and blood the consistency of pink water was gushing out of his nose.

9. Angus Junior was taken to Great Ormond Street Hospital (GOSH). At the hospital, I was accused of leaving Angus Junior's symptoms for too long (despite my having taken him to hospital when he was six weeks old) and was told that he might not make it through the night.

10. Fortunately Angus Junior pulled through and the following morning all of the family had to go down to GOSH to be tested. It was at this time we found out that Angus, Angus Junior and Mark had von Willebrand's disease. Research told us that von Willebrand's disease was an inherited bleeding disorder also known as haemophilia which meant that Angus and our sons were liable to bleed more than normal after minor surgery.

11. Angus was one of five children. As a result of his diagnosis of von Willebrand's disease, Angus' siblings were also tested for von Willbrand's disease in and around 1974/75. It was found that all of Angus' siblings had von Willebrand's disease, and this had passed on to some of their children and grandchildren. GRO-C also had the disease, as does GRO-C The attached family tree exhibited at WITN1002002 shows all of the members of Angus' family who had von Willebrand's disease. I also believe that Angus' mother was a carrier.

12. I have had sight of some of Angus' medical records to help me understand and recall events given the amount of time that has passed. I have noted a lot of discrepancies within these which I will come to later in my statement. However, the first discrepancy I noted was that some of the records state that Angus was diagnosed with severe phenotype Type 1 von Willebrand's disease, whilst other records state that Angus' von Willebrand's disease was moderate. In my opinion Angus' von Willebrand's disease was not severe but

moderate, as he led a normal life and didn't even know he had the disease up until this point.

13. Angus had his tonsils removed at the Royal Free Hospital before we met. At the time he didn't know he had von Willebrand's disease.

14. Angus suffered from frequent and severe nosebleeds before being diagnosed with von Willebrand's disease where he would lose pints of blood at a time, but these were never investigated. Due to the frequency of his nosebleeds, Angus had surgery to his septum in the 1970s in Huntingdon to try and relieve the amount of nosebleeds he was suffering. During the surgery Angus suffered a perforated nasal septum. However, Angus still suffered with a lot of nosebleeds following this. The clinical note attached and exhibited at WITN1002003 shows how frequent his nosebleeds were. In the period from May 1987 to June 1991 he suffered with 38 nosebleeds and this was not including those which he did not attend hospital for.

15. As GOSH is a children's hospital, Angus was transferred to the Royal Free Hospital for treatment of his von Willebrand's disease in and around 1969. It appears to be the case that Angus was usually treated with cryoprecipitate. He did not receive any treatment for his nosebleeds before this.

16. As well as suffering with nosebleeds, Angus also suffered with bleeding from his rectum. This meant that Angus had a severe iron deficiency anaemia and had to have iron therapy which resulted in him having constipation and problems with haemorrhoids. .

17. Upon reading Angus' notes, I noted that a lot of them refer to Angus also being hypertensive. I do not recall Angus having a high blood pressure and

the attached letter at exhibit WITN1002004 from Robert Greenbaum to Dr Lee dated 3 January 1983 suggests Angus was not hypertensive:

> *"I am not at all convinced that he has sustained hypertension…"*

18. From in and around 1992 – 1993, Angus had to self-inject himself with Haemate P (a form of Factor VIII) to keep his von Willebrand's disease under control. Angus was also given Haemate P each time he had a bleed or before surgery. It is therefore impossible for me to pinpoint exactly when Angus contracted hepatitis C. However, a letter from Christine Lee, Professor of Haemophilia at the Royal Free Hospital to Dr Patch dated 3 February 1999 (attached as Exhibit WITN1002005) states that it is thought Angus was infected with hepatitis C in 1980.

19. I have been through the records my solicitors have for Angus which they received from the Royal Free Hospital but the key records from when it appears Angus was infected (i.e. 1980) are not there. The clinical notes jump from November 1978 to November 1986 and the correspondence does not start until January 1987. I am therefore taking steps to locate the missing records to better understand how Angus became infected.

20. However, my son Mark has obtained a more complete set of records and when he started researching into how he, his father and brother came to be infected with hepatitis C, he found that it appears Angus was treated with contaminated blood products following an eye graze. The clinical note and consultation sheet in relation to this injury are attached and exhibited at WITN1002006. Mark also found the following note (attached and exhibited at WITN1002007):

> "*<u>TREATMENT:</u>*

Cryo only until January 1980 when became allergic to it.

BPL HL 2644 – 1st dose on 11/1/80.

LIVER FUNCTION TESTS:

Serum AST slightly elevated 1975 and 1978. Marked rise 28/2/80, approximately 6 weeks after first exposure to BPL.

HB$_s$ Ab Positive 11/1/80 before treatment with BPL"

This note correlates with Christine Lee's opinion that Angus was infected with hepatitis C in 1980 and is supported by Angus' C1 and C2 hepatitis survey forms attached and exhibited at WITN10021008. The treatment note attached and exhibited at WITN1002009 shows the details of the BPL Angus was given on 11 January 1980.

21. In 1990 (the exact date is unclear), there is a letter from Dr Lee which states that Angus' anti-HCV was positive on 5.3.1987. A copy of this letter is attached and exhibited at WITN1002010. This letter does not have an address on it and was never received by Angus. Angus and I were therefore unaware that he had hepatitis C.

Other Infections

22. I do not believe that Angus received any infections other than HCV as a result of being given infected blood products, but we know now that Angus was infected with hepatitis B as set out in the note already exhibited at WITN1002007:

"HBs Ab Positive 11/1/80 before treatment with BPL"

This was news to us.

23. However, Angus was never told that he could be at risk of CJD. In a clinical note by Christine Lee dated 8 January 1999 (attached and exhibited at WITN1002011), Professor Lee states the following:

> *"I have written a letter informing that batch 6406641 has been withdrawn by Centeon the manufacturers of haemate P…*
> *A donor contributing to the pool of plasma in the US had CJD. It is FOA policy to withdraw such batches…*
> *To discuss at next consultation."*

Yet the letter that Professor Lee sent to Angus on 12 January 1999 (copy attached and exhibited at WITN1002012) simply says that the batch has been withdrawn but does not mention why, and this wasn't discussed at Angus' next consultation.

Consent

24. I believe that Angus was treated with Factor VIII without his knowledge. He did not consent to the change in treatment, the hospital just went ahead and done it without giving him adequate information. We were not informed of the change to Angus' treatment or warned or advised of any risks involved in being treated with Factor VIII.

25. I believe that Angus was treated with Factor VIII as part of research. When Mark started to research into how he, his father and brother had all become infected with Hepatitis C, he came across a study entitled "*Short incubation*

non-A, non-B hepatitis transmitted by factor VIII concentrates in patents with congenital coagulation disorders". A copy of this study is attached and exhibited at WITN1002013. The authors of this study, amongst others are Bamber M, Kernoff PB and Thomas HC. When going through Angus' records, I noted that some of Angus' test results refer to extra samples being taken for Dr Bamber and Dr Thomas. Copies of these records are attached and exhibited at WITN1002014. As far as I'm aware, these doctors didn't need extra samples from Angus for anything else and this was never discussed with us. I can therefore only conclude that samples from Angus were being taken by these doctors for the purposes of research without our knowledge.

26. Mark and I also strongly believe that the list of the patients studied on page 474 of the study (copy also exhibited at WITN1002013) refers to Angus, Angus Junior and Mark. We believe that patient 11 is Mark, patient 18 is Angus and patient 19 is Angus Junior. What is worrying is the fact that the study was published in 1981 and refers to the fact that it was carried out over a period of at least six months. Angus was given infected factor VIII in January 1980. Allowing time for the putting the study results together and publishing it, the study could have well have started when Angus was given infected factor VIII or before.

Impact

27. Angus had ongoing problems with abdominal pain. The attached letter at WITN1002015 from Edward Tuddenham to Dr Pote notes "*pains in the left upper quadrant*" as early as November 1982. The same letter notes that Angus' "*Liver function tests were normal*" and "*AST and ALP – normal.*"

28. Angus also suffered with aches and pains in his joints, especially in his knee. I understand both the quadrant pain and joint pain can be symptoms of hepatitis C.

29. Angus was also treated for bladder/urinary problems including kidney stones and was anxious about developing prostate cancer as stated in a letter from Susan McGoldrick to Dr Pasi dated 9 July 1998 (attached and exhibited at WITN1002016):

> *"I recently saw Mr Stewart secondary to his complaints of knee and back pain. As you undoubtedly know he has a particular anxiety regarding prostatic cancer as his father died from the same and he is particularly worried that these pains may be secondary to metastasis or from a primary prostate tumour".*

This letter does not make any mention of Angus' hepatitis C infection. Fortunately Angus did not develop prostate cancer but I understand that whilst his urinary problems may not be directly linked to the hepatitis C, the stress of living with hepatitis C could have caused these symptoms.

30. During a hospital admission in and around 1991, Angus was put on an aids ward because of his bleeding. During this stay Angus started to show signs of depression; he would cry at TV programmes and the news, and had some loss of appetite whilst in hospital. When he was asked by the Haemophilia Centre why he was depressed, Angus confirmed it was the fact that he had been put on an aids ward. He was referred to a psychiatrist who diagnosed him with a mild-moderate depressive disorder and he was prescribed antidepressants.

31. There is a letter from Dr Lee to Dr Miller dated 12 March 1991 which states that Angus was reviewed on 8 March 1991 (copy attached and exhibited at WITN1002017). There is no referral in this letter to Angus' Hepatitis C infection or any treatment of the same. Dr Lee simply states:

> *"...I feel I have explained to him about non-A non-B hepatitis and the possibilities of that kind of treatment in the future."*

Angus had been to hospital 10 times between the date of the letter from Dr Lee in 1990 (already exhibited at WITN1002010 and not received) and this review, and his infection and treatment were not discussed once – this can be seen from the records attached and exhibited at WITN02018.

32. Further, a letter from Christine Lee to Dr Birger dated 17 April 1991 (attached and exhibited at WITN1002019 refers to an abdominal ultra sound Angus had done on 21 February 1991. Again, there is no mention of this ultra sound in Professor Lee's letter to Dr Miller dated 12 March 1991.

33. A letter from Eleanor Goldman, Associate Specialist at Royal Free Hospital to Dr Lipkin, Consultant Cardiologist also at Royal Free Hospital dated 8 July 1993 confirmed that Angus was "*...anti-HIV negative and anti-HCV positive with persistently abnormal liver function tests.*" A copy of this letter is attached and exhibited at WITN1002020. I can see no evidence that Angus was referred to have his persistently abnormal liver tests investigated at this time.

34. In 1994, Angus had to retire early from his job with BT on the grounds of ill health. I note that the reason given on Angus' sickness certificates for his retirement was due to back problems. This is not true. Angus did suffer with

a back injury in 1985 but this never stopped him from working and going about his everyday life. He retired as a concoction of everything. There was therefore more burden on me to work and we just managed to live but things were tight financially. However, following retirement Angus performed a lot of community work which he found quite rewarding. As haemophilia affected so many members of his family, Angus wanted to do whatever he could to help research this disease. Angus helped to collect money for the Katharine Dormandy Trust for Haemophilia & Allied Disorders which supported basic research into gene therapy for haemophilia. He was still collecting money the year he died.

35. Angus had been a smoker but he stopped smoking in and around 1981. There is a lot of reference in Angus' records to him drinking a lot of alcohol. Again this is not true. Angus and I went down the social club at the weekends and Angus would have a few drinks then, but other than that he didn't drink and certainly not as much as his records appear to suggest. He was just a social drinker like anyone else and didn't drink during the week or in the home as a rule. If he had known that he had hepatitis C then he would have given it up completely.

36. It was noted in March 1996 that Angus had an enlarged liver and mildly enlarged spleen. A clinical note dated 16 December 1996 (copy attached at exhibit WITN1002021) confirms that Angus' liver disease appeared to be "*multifactorial due to chronic hepatitis C, excessive alcohol consumption and steato-hepatitis against a background of gross obesity.*" Given what I have said above, I do not agree that Angus' liver disease could have been due to excessive alcohol consumption.

37. Angus was reviewed in the Combined Liver/Haemophilia Clinic on 27 September 1999 and it was noted that Angus had features of chronic liver disease "*with spider naevi and liver palm, but no evidence of hepatic ascites.*" Dr David Patch and Professor Christine Lee were of the view that "*an ultrasound would be of little benefit*" because Angus would almost certainly "*have a fatty liver and this would be hard to interpret*". A copy of this letter is attached and exhibited at WITN1002022. This is the first referral to Angus having chronic liver disease.

38. The letter from Dr Lee to Dr Miller dated 12 March 1991 already exhibited at WIT1002017 goes on to say:

> "*He does have a longstanding problem with haemorrhoids and this will not help his anaemia. I have therefore referred him to Mr Lewis.*"

A letter from Christine Lee to Dr Malik dated 22 March 2000 (attached and exhibited at WITN1002023) states that Angus had "*probably been bleeding PR*". A further letter from Mr Lewis to Professor Lee dated 24 January 2001 and exhibited at WITN1002024 states that:

> "*Certainly the polyps, diagnosed at colonoscopy in July 2000, could not possibly be responsible for his anal symptoms or his bleeding.*"

10 years on from the referral to Angus' haemorrhoids in 1991, the doctors were still investigating Angus' haemorrhoids and bleeding. Mr Lewis states that Angus' PR bleeding wasn't coming from his polyps, so it must have been coming from somewhere else.

39. Angus developed late onset mild diabetes later in his life which he took tablets for. We were never told that this could be linked to Hepatitis C.

40. As mentioned previously at paragraph 27, Angus suffered with abdominal pain. Angus used to tell me that he could feel his liver when he pressed on this area. However, this wasn't investigated by the Haemophilia Centre until in and around August 2001, a good 10 years later. In a letter from Dr Patch and Professor Lee to Dr Malik dated 20 August 2001, Dr Patch and Professor Lee indicate that the pain could possibly be linked to the development of a hepato-cellular carcinoma. A copy of this letter is attached and exhibited at WITN1002025.

41. The same letter states that Angus was too overweight to have a CT scan. This is surprising as the clinical note dated 16 December 1996 already attached and exhibited at WITN1002021 refers to a CT examination of Angus' abdomen and liver on 3 January 1997, suggesting that Angus had had CT scans in the past.

42. A further letter from Dr Patch and Professor Lee dated 10 December 2001 (attached and exhibited at WITN1002026) notes that the repeat ultrasound Angus had following his appointment in August 2001 showed no evidence of hepatoma.

43. By July 2002, Angus was feeling quite unwell and was in and out of hospital every couple of days. On 23 July 2002, I was visiting Angus in hospital and went to get a coffee. When I came back, Angus was upset. He told me that he had been visited by Dr Thynn Thynn Yee who had told him that he had a big tumour, it wasn't one that they could help with and then walked off.

44. Angus underwent a MRI on 24 July 2002 which showed that he had an enlarged liver and hepatocellular carcinoma. Unfortunately this was inoperable.

45. On 25 July 2002, Dr Yee wrote to Dr Malik. In this letter (copy attached and exhibited at WITN1002027), Dr Yee stated:

> *"An alpha-fetoprotein done at that time showed that it was very raised at 93,913 kU/L, the normal limits being less than 11.3."*

In the letter from Professor Lee to Dr Malik dated 20 August 2001 (already exhibited at WITN1002025), Angus' alpha-foetoprotein had increased to 72. Therefore, a year prior to Angus being diagnosed with liver cancer, the doctors should have been aware that Angus may have cancer.

46. This diagnosis was devastating for Angus and all of us. Angus always tended to put on a brave face but he struggled with this diagnosis and became tearful on occasions. He found it difficult to talk about his disease. He tried to be philosophical but he worried about how he would cope with cancer and about his children.

47. On reviewing Angus' records I came across a Do Not Attempt Resuscitation (DNAR) form dated 2 August 2002 (attached and exhibited at WITN1002028). To me, it looks like the doctors had already decided Angus' fate between themselves. Also, I would like to know who authorised this as I was never consulted about it.

48. Angus had problems sleeping after finding out about his diagnosis. He would have violent nightmares that frightened him and he was scared to go to sleep. When he had to stay in hospital overnight he was sometimes sedated or

given sleeping tablets. I understand that fatigue can be a symptom of chronic infection with hepatitis C.

49. Angus' health deteriorated rapidly after being given his diagnosis of liver cancer. I was aware that Angus did not have long left to live and so informed my family to visit him. All of Angus' grandchildren came to visit him at our home and my son Angus Junior flew back from Hong Kong to be with his father.

50. The pain Angus was in started to get unbearable for him. It would keep him awake at night and he started to suffer with nausea.

51. On 7 September 2002, Angus died as a consequence of massive cancerous tumours in his liver which were secondary to his Hepatitis C.

52. I am glad that Angus didn't know about this scandal or the fact that his two sons have also been infected. Angus should have been told the truth and if he had known in time, he could have been given early treatment or a liver transplant when there were signs that he had liver cancer. Instead he didn't receive any treatment whatsoever.

53. I was, and still am absolutely devastated about Angus' lack of treatment and death. I watched him in pain for 20 years and the doctors did nothing. Angus became too unwell to go anywhere and we stopped going to the social club. The impact of Angus' death especially effected our 12 grandchildren who Angus saw frequently.

Treatment/Care/Support

54. To keep his nosebleeds under control, Angus had to inject himself with prophylactic treatment of factor VIII twice a week of approximately 2000 -

3000 units each time. I had to help him with this. Despite this treatment, Angus still suffered with a number of nosebleeds. His prophylactic treatment was therefore changed in May 1994 from factor VIII to Haemate P to which he responded well.

55. The letter from Dr Christine Lee to Dr Miller dated 12 March 1991 already exhibited at WITN1002017 states that Dr Lee discussed a treatment with Angus:

> *"We are now in the process of treating some of our patients who have chronic non-A non-B hepatitis with interferon. I mentioned this study to him, but he said "we can leave him out"."*

I find it very hard to believe that Angus would have said this. He was not like that and if treatment had been available he would have taken it.

56. There is a clinical note dated 19 May 1992 which states that Angus was a potential candidate for the ribavirin trial. A blood count report dated 2 June 1992 states that Angus was on the trial by that date. Copies of both of these documents are attached and exhibited at WITN1002029.

57. The records state that in June 1993, Angus attended a trial of high purity von Willebrand's factor and that within half an hour of having the high purity factor, Angus began having a "squeezing" chest pain and a sharp radiation pain in his upper right abdomen which lasted for approximately two hours. The same note suggests that Angus had been suffering with shortness of breath for 12-18 months prior to this and would get puffed out after climbing the 13 steps in our home but that he could walk long distances on level ground. This is not

true, Angus did not suffer with shortness of breath and was quite capable of walking up stairs. The same note also suggests that Angus had also been suffering with pins and needles in all of the fingers of his left hand consistently for several weeks before the trial but I don't remember this being the case.

58. Dr Pasi, Consultant at the Haemophilia Centre treated Angus for years and on several occasions he suggested treatment for Angus. This can be seen in the attached letter from Dr Pasi to Dr Toag dated 12 September 1994 (copy attached and exhibited at WITN1002030) where Dr Pasi states:

> *"I have suggested that we repeat a CT scan in the near future and then consider further therapy for his HCV related hepatitis."*

59. Dr Pasi again refers to treatment for Angus in a letter to Dr Mistry dated 20 November 1996 (attached and exhibited at WITN1002031):

> *"However, I think he would appreciate the opportunity to consider his hepatitis C infection and where we should take this at present."*

60. On the same date, John Pasi wrote a letter to Dr Malik (attached and exhibited at WITN1002032) confirming that Angus "*should be on regular ranitidine because of chronic gastritis*".

61. Further, a letter from Dr Coghlan to Dr Lee dated 13 March 1995 (attached and exhibited at WITN1002033) confirms that Angus could have coronary surgery:

> *"He has been previously informed that his makes him too high risk for coronary surgery. This is not my recollection from cases I have seen at Harefield..."*

62. Despite these comments by both doctors, it seems to me that Professor Lee always seemed to overrule recommendations for treatment. For example, in the note dated 16 December 1996 already exhibited at WITN1002021, Professor Lee says:

> *"we are unable to recommend combination therapy due to presence of ischaemic heart disease".*

At this time, Professor Lee was already aware from the letter from Dr Coghlan dated 13 March 1995 that Angus could in fact have coronary surgery if it was found that he did have ischaemic heart disease, and then he could have had the combination therapy. Yet it would appear from a letter from Dr Coghlan to Dr Malik dated 20 June 1999 (attached and exhibited at WITN1002034) that Angus was not referred for angiography until some four years later. In any event, in the letter dated 22 March 2000 already exhibited at WITN1002023, Christine Lee reported to Dr Malik that Angus did not have coronary artery disease:

> *"He has also been investigated recently with an angiogram under Dr Cockland, the consultant cardiologist because of chest pain. However he has reported that his ejection fraction is 70% with good LVF and that both coronary arteries are good. Thus he does not seem to have coronary artery disease."*

Despite knowing this, Professor Lee still did not refer Angus for treatment.

63. In a clinical note dated 19 June 2002 (attached and exhibited at WITN1002035), Professor Lee advised a S/R:

> "↓ *Hb probably 2° to GI bleeding*
>
> *to cont with current prophylaxis and not to investigate actively"*

Professor Lee told the S/R not to investigate Angus' bleeding. The next note after this one is not dated until 19 July 2002, suggesting that Angus was not seen for a month even though Professor Lee and the other doctors were aware that Angus appeared to be bleeding internally.

64. In a letter from Dr Patch to Professor Lee dated 22 August 2002 (attached and exhibited at WITN1002036), Dr Patch stated that he thought Angus "*should be considered for Lipiodol I* ^{131}*."* This was two weeks before Angus died. There is nothing in the notes, and I do not recollect Angus ever being consulted about this treatment.

65. A letter from Dr Coghlan to Dr Malik dated 2 June 1997 (exhibited at WITN1002037) states that Angus was "*essentially free of angina."* Despite this, Angus was still not considered for treatment. This is confirmed in a letter from Dr David Patch to Dr Heath dated 27 September 1999 (already exhibited at WITN1002022) which states that Angus was "*very much living on borrowed time and we have no plans to consider treatment with antivirals."* I do not understand why Dr Patch states that Angus was "*living on borrowed time*". The letter then goes on to state that Angus had "*an appointment to be seen in the Combined Liver/Haemophilia Clinic in twelve months time."* If Dr Patch believed that Angus was living on borrowed time then I do not understand

why arrangements were not made for Angus to be reviewed again sooner. Dr Patch also does not confirm in this letter or at any other point why Angus could not be given treatment.

66. The letter from Susan McGoldrick to Dr Pasi dated 9 July 1998 already exhibited at WITN1002016 goes on to say:

> *"I know that he has had a number of x-rays of his knees and hips done, but I am unable to access the results as the films have gone straight to the haemophilia centre and were not reported first."*

Again it seems to me that some members of the Haemophilia Centre were trying to intervene to avoid having to give Angus treatment.

67. I also believe that Angus was treated with unlicensed products. There is a letter from John Pasi to Mr West of Hoechst Roussel Limited dated 18 December 1995 (copy attached and exhibited at WITN1002038) which states:

> *"This is to inform you that I intend to use Haemate P supplied by Hoechst Roussel Ltd but not cleared by the NIBSC..."*

68. A further letter from Dr Pasi to Dr Toag which is undated (exhibited at WITN1002039) confirms that Angus' treatment was swapped from BPL8Y to Haemate P but does not mention the fact that the Haemate P is unlicensed.

69. Angus was told at a clinic on 11 October 2000 that he could not have his haemorrhoids injected because of his bleeding disorder (letter from Christine Lee to Dr Malik dated 31 October 2000 attached and exhibited at WITN1002040). Professor Lee intervened and Angus did eventually receive

injections for his haemorrhoids on 6 June 2001 which stopped his rectal bleeding for a time. However, I find it surprising that in this letter Professor Lee doesn't once discuss Angus' hepatitis C infection and instead refers Angus to other doctors in different fields.

70. When Angus was diagnosed with liver cancer in July 2002, he was referred to the palliative care nurse for support. The nurses would come during the day and in the evening to top up Angus' painkillers, and some members of the Haemophilia Centre came to Angus' funeral.

71. No counselling or psychological support was ever made available to Angus, me or our family.

Financial Assistance

72. Angus was registered disabled and claimed Disability Living Allowance. He also received a travel permit from London Borough of GRO-C

73. Angus' notes state that in November 2001, Bexley and Greenwich Health Authority gave funding approval for Angus. I do not know what this was for and would like an explanation.

74. In and around 2010-2011, I received a pay out from the Skipton Fund. This was around £20,000 - £30,000 and two years later I received an extra £10,000 widow's payment. I now receive £450 a month from the EIBSS.

Other Issues

75. Unfortunately there was also a delay in my son Mark finding out he had hepatitis C. Following diagnosis, Mark began to look into things and started to question the treatment that he, my late husband and my late son Angus

had received from the doctors and nurses who had been treating them. Mark began researching to try and understand what had happened to them all.

76. I am extremely concerned that as a result of Mark's research, he came across two identical clinical entries in both my husband's Angus Senior records and my son's Angus Junior records. Both notes are dated 11/12/81 and state:

> "*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 like concentrate', there seems to be little alternative to carrying on with this because he has had bad reactions to cryo. Kernoff*"

A copy of my husband's note is already exhibited at WITN1002007. A copy of my son's note is attached and labelled exhibit WITN1002041.

77. I have further reason to believe that Angus was used for research. There is a letter from Professor Lee to Angus dated 29 January 1999 (attached and exhibited at WITN1002042 in which Professor Lee asks Angus to help with some research:

> "*We are studying the occurrence of fatigue in individuals with inherited bleeding disorders. We hope that you would be able to complete the enclosed questionnaire…*"

Angus' consent form to this research dated 3 February 1999 is also exhibited at WITN1002042. As part of his research, Mark came across a study entitled "*The natural history of HCV in a cohort of haemophilic patients infected between 1961 and 1985*". A copy of this study is exhibited at WITN1002043. Two of the authors of this study, amongst others, are T T Yee and C A Lee and the study is dated 2000. I understand that fatigue isn't really a symptom of von Willebrand's disease but rather a symptom of hepatitis C and certainly Angus did not suffer with fatigue before becoming infected with hepatitis C. I therefore believe that rather than using Angus' questionnaire results for research into the risk of fatigue in individuals with inherited bleeding disorders, Angus' answers were used as part of this study.

78. There is a letter from Dr Coghlan to Professor Lee dated 1 April 1999 (attached and exhibited at WITN1002044) where Dr Coghlan states that Angus was last seen by him in 1996. Yet the letter from Dr Coghlan to Dr Malik advising that Angus was free of angina is dated 2 June 1997 (already exhibited at WITN1002037), so Angus was in fact seen by Dr Coghlan during this time.

79. A letter from Dr GRO-D to Mr Warburton dated 20 June 1999 (attached and exhibited at WITN1002045) states that:

> *"I have a distressed letter from his GP because his condition has deteriorated markedly while we appear to have been sitting on our hands!"*

Although in her letter of 12 March 1991 Professor Lee states that "*it is not normally our practise to review people with von Willebrand's Disease*", several of Angus' records (including the same letter) refer to Angus being reviewed annually. Yet it appears that this did not happen.

80. There is a letter from John Pasi to Angus dated 2 April 1996 which refers to testing Angus' blood "*before and after treatment in a new machine*", and a further letter from John Pasi to Angus dated 30 April 1996 which says:

> *"Just a note to confirm that we can perform the special blood tests that I have mentioned to you..."*

I couldn't find any other reference to these special blood tests and a new machine in Angus' records and would like to know more about them. Copies of both letters are attached and exhibited at WITN1002046.

81. I find it unacceptable that the Trust refused to treat Angus for his hepatitis C, especially given the fact that he contracted his infection as a result of being given infected blood products by the Trust. Dr GRO-D and Christine Lee would not recommend combination therapy treatment in 1992 because of Angus' ischaemic heart disease which Angus did not have. Dr Patch and Dr Lee

refused to give Angus an ultrasound in 1999 because they "assumed" he would have a fatty liver.

82. When going through Angus' records I came across a letter from Dr Telfer to Angus dated 7 May 1992 asking if I would be willing to undertake a hepatitis blood test and answer a questionnaire. We never received this letter and following Angus' death I was never advised to be tested for Hepatitis C which I think would be common sense. A couple of years ago I was tested by my own doctor as I started suffering with bruising and itching. Fortunately my tests came back clear but my liver is elevated because of the stress I have been under.

83. I have several medical conditions myself. About six months after Mark was diagnosed with hepatitis C, I became depressed and was prescribed Prozac. My depression has worsened over the years and I now take Mirtazapine. I believe that the depression came to a head because of Mark's diagnosis. Mark moved in with me in August 2009 following his diagnosis of hepatitis C. He told me he wanted to be alone and separate from everyone.

84. I also suffer with dizzy spells and falls. This has been investigated by the doctors who have said that it is due to high blood pressure and stress.

85. The contaminated blood scandal has completely ruined my life. I believe my husband was deliberately infected so that he could be used for research and was not offered treatment as he was monitored as part of studies. Not only have I lost my much loved husband and son, I also have to see the pain my son Mark endures everyday living with the consequences of HCV and this scandal.

Statement of Truth

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

Signed GRO-C

Dated 27 SEP 2019