Witness Name: Julie Anne Williams
Statement No.: WITN0620001
Exhibits: **Nil**
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JULIE ANNE WILLIAMS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 13 November 2018.

I, Julie Anne Williams, will say as follows: -

Section 1. Introduction

1. My name is Julie Anne Williams and my date of birth is GRO-C 1964. My address is known to the Inquiry. I am currently working as a Teaching Assistant at a school.

2. I intend to speak about my late husband, Darren Williams. He was born in 1967 and passed away in January 2015. We married in 1993 and we have one daughter, who was born in 1996. My daughter (W0642) is also providing a statement to this Inquiry.

3. My husband was infected with hepatitis C through Factor VIII blood products. In particular, I will detail the nature of his illness, how the illness affected him, the treatment received and the impact it had on him and our lives together.

4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

Section 2. How Affected

5. Darren was diagnosed with severe haemophilia A at 10 months old, when he was at Great Ormond Street Hospital. I believe he remained a patient there until he was approximately 8 or 9 years old, after which he transferred to the Royal Free Hospital also in London.

6. Darren was initially given cryoprecipitate to manage his Haemophilia, however after some time he began using Factor VIII. I cannot remember the precise start date but it was in the 1970s when it was new and whilst he was at Great Ormond Street Hospital.

7. Before Darren changed to Factor VIII, his mother was told that the blood product was new and it would work quicker - she was not told about any risks of infection. Darren's father did not go along to any appointments so he would not have known either. However Darren's mother is not the type of person to take risks, if she had been informed there could be potentially unknown infections/viruses within the new treatment, she would not have subjected her only child to them. If she had known otherwise - she would have had Darren continue using cryoprecipitate.

8. Whenever Darren had a bleed he would go to the Hospital where they administered Factor VIII to him. However when he reached a certain age, he would inject himself as and when he needed it - all these injections were recorded on a monthly sheet which included Factor VIII product brand and batch number, date of injection, amount of units used, why used (bleed/prophylaxis) and site of bleed. All forms were returned to the Haemophilia centre - The Royal Free, Hampstead - which should mean there is a record of all batch numbers taken and possible risks within the batch numbers.

9. When Darren was young and at the Royal Free Hospital, his mother remembers seeing blue and green bottles of Factor VIII. The Nurse said that he should be given the UK sourced one and not the American one but we cannot remember which one he ended up having.

Diagnosis

10. In July 1990, Darren received a letter from the Royal Free Hospital saying that he was hepatitis C positive.

11. However when I spoke to his mother she said she believed that he was hepatitis C positive much earlier as he had a dentist appointment when he was younger and the receptionist said they needed him to go last in the queue - the dental nurse said this was because he had a contaminant in his blood but Darren's mum just thought that it was to do with his haemophilia. However with hindsight, Darren's mother now feels that it was because he had hepatitis C as he was never asked on previous occasions to go last in the queue because of the Haemophilia.

12. The hepatitis C letter did not mean much to Darren or to us as it did not seem a big thing at the time as it is now - he was just relieved that he did not have HIV. However we never told any friends, work colleagues or family that Darren had hepatitis C, as we didn't want the same stigma attached to us as was attached at the time concerning HIV.

13. I believe Darren would have gone to talk at his next review appointment at the Royal Free Hospital following this letter but do not know what was discussed - I was not with him as I didn't start going to his appointments until after we got married in 1993. I am not certain but I do not think they had a detailed discussion about hepatitis C until there was some cirrhosis of the liver, which they seem to imply was as a result of drinking too much alcohol. Although Darren pointed out on more than one occasion that he was not a heavy drinker, this was always met with disbelief for some reason. I do know that my daughter also encountered

this reaction from fellow peers at school when she informed them that her dad needed a liver transplant. This seems to be the stigma that is associated with problems of the liver. In Darren's case this was not the reason he needed the transplant; it was because of the hepatitis C.

14. We were once asked at the Royal Free in the early days to take part in and anonymously complete a questionnaire, which would give them an idea of how hepatitis C was transmitted. They took me in a room and they took Darren separately in the room and asked very personal and intimate questions, and they completed the forms.

Section 3. Other Infections

15. Darren was infected with hepatitis C and another hepatitis strain which he found out about later when he went onto the Interferon/Ribavirin treatment after having more blood tests.

16. He also received a letter from the Royal Free in connection to vCJD and the possibility that he could have been contaminated with this virus as well; this put a lot of strain on the family again trying to get our heads around this piece of devastating news and what it could mean for Darren.

Section 4. Consent

17. Darren was tested for hepatitis C on 21 January 1990 but he was unaware of the test having taken place and as such did not give his consent.

Section 5. Impact

18. Fatigue was the main effect of the hepatitis C virus in the early days.

19. Between the diagnosis in 1990 and 2001, Darren had treatment for hepatitis C using Interferon and Ribavirin but it did not work as he had a reaction to it which made him very ill. Otherwise he was just went for tests and he was being monitored.

20. In 2001 Darren had a review appointment with Dr Patch, a Liver Consultant at the Royal Free, who informed him that he needed a liver transplant due to cirrhosis of the liver and that his life expectancy without one was around 2 years. Darren asked Dr Patch what he would do if it were him and Dr Patch replied "If you were my brother I would tell you to get on the list immediately". Dr Patch and the team were lovely and very supportive.

21. After the appointment, Darren just sat in the car for around 30 minutes and said to me "Julie just let me think for a second, I need to get my head around this". Darren was devastated.

22. Later in his life, he wrote about this event in his notes dated 9 April 2014, 'My life and the lives of my family was turned upside down, I had lived with Haemophilia and for the most part tried not to let it affect my everyday life and until this hospital appointment I had succeeded.'

23. In June 2002, he was placed onto a transplant list and 2 months later he had his first liver transplant at the age of 36. I remember we received a call in the middle of the night from the Hospital and they said a liver had been found and Darren needed to have a transplant - our daughter was about 5/6 years old at the time.

24. Before the liver transplant he was very tired but after he realised how different he felt as he had more energy. He also did not have haemophilia anymore and that helped him.

25. However a year after the transplant, he had a knee replacement and it went downhill from there. Darren developed varices of the oesophagus and he would be vomiting a bucket full of blood - we now know this was

a side effect of the hepatitis C. He also developed skin cancer - he had melanoma in the crease above his eye and after he hit his head, it was on his scalp. He also developed melanoma on his face which meant that they had to cut his face to remove it - this was an awful time for him. His face was very painful, which the painkillers did not seem to touch - his face had swollen up to 2/3 times its size and he could not eat properly. This was another very tough and stressful time for him.

26. Darren also developed ascites, bowel disease and diabetes, which led to significant weight loss and the low immune system as a result of the transplant, which meant he was susceptible to many other health issues.

27. In 2012, Darren found out that the hepatitis had come back more vigorously. Professor Burrows at the Royal Free Hospital told him that he needed a second liver transplant but he could not be put on the waiting list until he cleared the hepatitis C. He was told again that he needed the transplant within 2 years (we did not know it then but within that 2 years Darren would be gone).

28. In January 2013, Darren was allowed to start a new course of treatment on compassionate grounds. This involved Interferon, Ribavirin and a new experimental drug, which was not fully licensed in the UK called Soforsbuvir. He was on this treatment for 6 months.

29. Darren was placed on the liver transplant list after 3 months of the treatment. However 6 weeks after the treatment ended, the hepatitis C was back more aggressively - he was removed from the list, which left him shattered and devastated.

30. In October 2013, Darren started another course of partially unlicensed treatment involving Ribavirin, Soforsbuvir and Daclatasvir. The treatment finished on 10 March 2014. In Darren's notes dated 9 April 2014, he said about this treatment that 'It was hell, but I was always positive and hopeful that this regime would work'.

31. Darren was told that he needed to be free of hepatitis C for 6 months post-treatment before he will be placed back on the liver transplant list. Darren was clear of hepatitis C by the end of 2014.

32. However by this point, he was too ill to be put onto the transplant list - I think they should have changed the order so that he had the transplant first then they tackle the hepatitis C once he was stronger to cope with the awful side effects of the treatment. I remember that he was part of a study in 2013/2014 which found that people should be put on the transplant first and then they focus on the hepatitis to be removed. (I believe Darren would still be with us today if they had allowed the transplant to go ahead first.)

33. Darren suffered from various side effects from the treatments including, internal bleeding, dehydration, various infections, nausea/vomiting (sometimes blood), bloating/swelling, memory loss, shakes, insomnia, mood swings, joint aches/pains, cramps, sweating, feelings very cold, diarrhoea, loss of appetite, bad aches and a cloudy brain.

34. He also suffered from Hepatic Encephalopathy. He used to rock in his chair and forget things. He did not know where things were - he would stagger around as he was unsteady on his feet and head into the kitchen but he could not navigate around our house which we had lived in for 21 years, he forgot where rooms were and then get really angry and frustrated. He would want his shoes on even though they were already on him or ask me to take them off when he wasn't wearing them and get frustrated so I would pretend to take them off when he asked. It was like dementia. He couldn't walk up and down the stairs and so we had to sleep downstairs on a pull-out couch, sometimes we slept on cushions on the floor as I was scared he would fall out of the bed. I was also frightened that he would wander outside. We didn't get much sleep during this period.

35. Around the beginning of December 2014, Darren was having more frequent and longer cloudy episodes. We went to a scheduled

appointment and from there he was admitted via A&E onto the day ward at the Royal Free as there were no beds available on the Liver ward - he said that he couldn't breathe properly.

36. A week before Christmas, he called me to say that he felt awful and that the doctors were not listening to him as he was still on the day ward - they said that his lungs were clear but he felt he still could not breathe properly (he ended up having pneumonia). I telephoned Janet Catt, Darren's Hepatology nurse who went to see Darren and calm him down until I arrived. We had known Janet for years and I only have high praise for her.

37. When I got to the hospital, Darren was in a state. On the Friday before Christmas, Darren's mother arrived. He then took a turn for the worse. They took him to the ICU and put him on a strong breathing machine - Dr. Patch had previously told him that if he ended up on a ventilator he wouldn't be strong enough to get off it, so Darren tried really hard to cope with the breathing machine but couldn't manage anymore. Darren could not move, go to the bathroom or eat - the doctors were now saying that he had pneumonia.

38. As Darren was on a breathing machine that pushes the air into him, he could talk a little bit. Once on the ventilator, he was unable to communicate. While he was in the ICU, the doctor came in and said that he wouldn't be able to go on the transplant list anymore even if he recovered from this set back as he would never be able to get himself back to a fit state to survive a transplant, and they had a duty of care to give a new liver to someone who had a chance of survival - just what I needed to hear while watching my husband fight for his life.

39. He was in so much pain on a kidney dialysis machine and on so many drugs - they were keeping him sedated and he was unable to communicate. He woke up briefly once when our daughter was with him but after that he didn't wake up again. The doctors told us that they would turn the machines off but his parents didn't want this. They then

wanted me to make the decision which I couldn't do. The doctors eventually turned it off and Darren didn't wake up - he slipped away. Darren passed away on 8 January 2015 of multiple organ failure via pneumonia.

40. The hospital wouldn't release Darren's body because of his hepatitis C infection, even though he had cleared it leading up to his death. They kept him in a morgue and he couldn't even go to the chapel of rest. I had to fight for his body to be released so he could be placed and buried in his own clothes; the funeral parlour told us that they only released his body the day before the funeral and by that point he might not be in a good state to be viewed. A lot of people turned up for his funeral, even Dr. Patch. I have never seen so much people - he was so loved.

41. We always knew that his life expectancy was shorter than average but we just thought that he would end up in a wheelchair due to the haemophilia not that he would die so soon because of the effects of Hepatitis C. I also just thought that he would have a second transplant and he would be fine again. Despite this, the transplant he did have gave him another 12 years of life and he was glad to have those 12 years with our daughter and me and for that we are eternally grateful for to his original donor and family.

42. In terms of our life together, we both tried to do everything as normal as we could. I remember when Darren was in a day ward and he apologised to me for having to do everything for him and he shouldn't have had to apologise to me. He thought it was his fault and it wasn't. To me this was our life and we lived around it.

43. However there was a definite impact on our daughter, which started from a young age.

44. Our daughter saw her father in hospital when she was 5 years old. I don't think that helped her as ever since then, she has hated injections and she gets hysterical whenever she sees an oxygen mask.

45. Darren also missed our daughter's school drama performances as he would be in hospital - I would usually rush back from the hospital so that at least one of us could be there for her.

46. Our daughter and I would always have our phones on us as Darren used to text us at certain times. I remember when she was at sixth form, if Darren didn't text or call her, then she would leave to go home to check if he was alright - our daughter was constantly worried about him.

47. In 2014, when our daughter went to university, she joined the Netball team and hurt her ankle quite badly. She had to come home to recover and it was during that period that she got to spend a full 6 weeks with her father before Darren went downhill.

48. Darren's parents blame themselves and they blame us, which made our relationship strained - his parents have not been to our house since he has passed.

49. I lost my father in 2017 and Darren should have been there to support me.

50. In terms stigma, we didn't tell anybody about the hepatitis C as it was a taboo subject.

51. Darren did very well in his career despite facing difficulties finding a job due to his haemophilia. However when he finally found a job, he was over the moon.

52. After some years in this job, his boss moved on but then headhunted Darren again. Darren then became Managing Director of a company but he was only in this position for 1 year before falling sick.

53. Darren had a great employer. He gave him full pay while he was unwell and told Darren to return to work on a part time basis when he was better. Darren did go back to work but he couldn't work properly anymore and became more and more tired. In the end he just stopped working and stayed at home. He lost his job and was devastated.

54. I went from full-time to part-time work with the bank. When our daughter was young, our neighbours would help with the school run and take her when I needed to stay with Darren. I then found a job as a Teaching Assistant, which was a God send. Our daughter had to try and go back to focus on University after we lost Darren.

Section 6. Treatment/Care/Support

55. There were no difficulties in Darren receiving treatment- he had a lot of respect for all the doctors on the ward.

56. However I remember one occasion when Darren was in a day clinic ward and they didn't know much about him – he needed to be on the Hepatology ward so that they could deal with his liver. Although the Hepatology doctors came to see him, he should have been on their ward in the first place.

57. Otherwise, the only stigma was at the end when he had died – the hospital held his body and refused to release it until a day before the funeral.

58. In terms of counselling, we were offered it through the Skipton and Caxton funds but we didn't use it. There was counselling offered to Darren whilst he was in the Royal Free Hospital.

Section 7. Financial Assistance

59. In 2004 Darren found out about the Skipton Fund from the Royal Free Hospital. He contacted them and they sent him a form, which was completed with the Haemophilia Centre at the Hospital. As far as I am aware, Skipton did not request further information after the application was submitted and there were no pre-conditions to make the application or receive payment. I do not think it was a long application process.

60. In August 2004, Darren received a lump sum payment of £20,000.00.

61. In October 2004, he received a further lump sum payment of £25,000.00 after receiving confirmation of stage 2 hepatitis C.

62. In April 2011, Darren received another payment of £25,000.00 from the Caxton fund. To the best of my knowledge, I don't believe that there were any preconditions imposed on him.

63. He also received monthly payments from the Skipton fund, which varied in amount and increased on an annual basis. However these payments stopped when he passed away. His last quarterly payment covering the period of November 2014 to January 2015 was paid to me.

64. After Darren passed away, I received a £10,000.00 bereavement payment and a £3500.00 funeral payment. I also started receiving another 1 year allowance from the government, which was paid on a monthly basis as I was not entitled to a widow's pension – Darren passed away too young.

65. Our daughter also received £300 per month towards her university studies but that has stopped as she is no longer there.

66. My thoughts on this financial system is that it is traumatic to complete all these forms, including income and expenditure, before you can receive any money.

67. I also remember whilst our daughter was applying to university we were on a good income due to Darren's salary. However by the time she enrolled, he stopped earning and I had to contact the Caxton fund for help. They said I had to exhaust all the government benefits first before they could help. Student finance could not help and so I went back to Caxton who ended up helping with living expense.

Section 8. Other Issues

68. What I want to stress was how it affected us after Darren's death as we couldn't use the chapel of rest and his body wasn't released on time.

69. It is so sad around Christmas because he isn't there and we all use to love Christmas but now it's a struggle putting up a Christmas tree.

70. The relationship between our daughter and her grandparents has suffered as we have moments where everything is stable with them and then moments where it is bad.

71. When our daughter turned 21 years old, Darren wasn't there. When she gets married he won't be there. He won't even be there to see his grandchildren and it is not fair that he and our daughter have to miss out on all this.

72. It is the worst thing imaginable seeing the person you love go through all the side effects as a result of an illness which they shouldn't have had in the first place.

73. Also what is upsetting is the difference in treatment and payments the infected people have received. Why does my Darren's death mean less as opposed to someone who lives in Scotland? Why are there differences in payment for people who are suffering with stage 1 or stage 2? Why should they be treated differently?

74. People need to know what has gone on and the impact this has had on infected/affected individuals. They need to know what infected individuals have and unfortunately are still going through. The infected/affected deserve answers and compensation. Also it shouldn't be just the people that have been left behind that are receiving apologies like David Cameron's pathetic apology. The infected still alive today need results now, they need to know that their loved ones will be taken care of.

75. As a haemophilic, Darren was unable to get life insurance among other things. As a result, I still have a mortgage, still have all the same bills to pay, but I do not even qualify for a widow's pension as Darren died apparently too young - how can this be right?

76. I want Darren's voice to be heard that is why I am doing this, because if he was still here with us he would be shouting as loud as he could.

Statement of Truth

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

Signed GRO-C

Dated 18/5/19.