Witness Name: Jade Williams
Statement No.: WITN0642001
Exhibits: Nil
Dated: 10/06/2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JADE WILLIAMS

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

I, Jade Williams, will say as follows: -

Section 1. Introduction

1. My name is Jade Williams and my date of birth is GRO-C 1996. My address is known to the Inquiry. I work full time as a school attendance administrator and live at home with my mum. I do some acting work in my spare time.

2. I intend to speak about my late father Darren Williams (GRO-C 1964 to 8th January 2015). He had been infected with Hepatitis C virus ("HCV") as a result of being given infected blood products to treat haemophilia.

3. In particular, I intend to discuss the nature of his illness, how the illness affected him, the treatment he 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. My father Darren Williams was born on GRO-C 1964. He had severe haemophilia from when he was a child. It was the blood products he received to manage the condition that infected him with HCV.

6. Initially, he was treated with cryoprecipitate, but was later administered with Factor VIII. No one was informed of any contamination risks when he switched treatment. I would say he was infected anytime from when he was given Factor VIII. He was initially treated at Great Ormond Street Hospital and later at the Royal Free Hospital.

7. During his younger years he was constantly in and out of hospital for bad bleeds, and this would mean his mum would have to call an ambulance for him to get treatment. My grandmother recalls being told that there was a new blood product available and that is was like a miracle drug that would stop the pain and work almost instantly, but she was told that it was no different to the cryoprecipitate which had been used before.

8. When they went back in for another bleed, a nursing sister (who had become close with my grandmother) stated that she did not want my dad to have any more of the American blood no reason was given as for why. She instructed them to wait for English Factor VIII from then on, which they did. My grandmother did not think anything of it at the time, merely thinking that the nurse preferred the English brand. However, she now strongly believes that the nurse knew the American blood was contaminated. To my Nan's knowledge my father only had 1 dose of American factor VIII that she was aware off.

9. My grandmother also remembers going to the dentist with dad for a morning appointment after he had been treated with Factor VIII, when he

was around 11. Once they arrived it was put back until the end of the day. When the receptionist was questioned why, they explained that dad was a contaminant risk and it was marked all over his file. My grandparents presumed it was because his haemophilia was so severe, but this had never happened before. From then onwards, all of his medical appointments would be the last in the day.

10. Dad was formally told of his infection with HCV via letter dated 24th June 1990. The letter explained that a test was taken on 9th January 1990 that came back positive for HCV, and to make an appointment for any additional information. My dad didn't know he had even been tested on the 9th, and to the best of my understanding he was completely unaware. I first saw the letter when I was 21, and found it very brief and impersonal. I think it was a very disrespectful way to tell someone they have a virus which is difficult to clear. It was also alarming to be told it could be sexually transmitted. Despite its shocking content, the letter did not offer any support. It didn't even explain what HCV was or the effects of the virus – the letter contained no helpful information at all.

11. I believe he did receive a blood transfusion in the early 2000s, during his 1st liver transplant, and possibly when he had his knee replacement.

Section 3. Other Infections

12. Dad did not contract any other infections as a result of being given blood products to treat his haemophilia.

13. He did receive a generic letter in 2000, which stated a batch of Factor VIII given to him might have been contaminated with vCJD. It merely said to be tested if concerned. Dad was so stressed after being notified of this. He believed he was so lucky only to have HCV and not HIV. When he was told about his contamination, he had been lucky not to contract HIV as it was the HIV pandemic. It was at the time

when it was all over the news that HIV was a male killer, and the stigmatism that came with the disease was that it was a 'Gay' disease.

14. To my knowledge he was only told that he could have vCJD, it was never diagnosed.

Section 4. Consent

15. As my father was a child, my grandparents gave consent to him receiving Factor VIII. They saw it as a miracle drug, because they heard how great it was. In hindsight they wish they had left him on the cryoprecipitate treatment, but they were not really given a choice really as they were not given the option to stay on the old treatment.

Section 5. Impact

16. In the two years prior to his death, while waiting for his second liver transplant, Dad became severely depressed. He was worried that he might not be able to have the transplant, and was under the impression that he was letting everyone down.

17. As he was confined to the downstairs of the house, the doors were widened in the event that he required a wheelchair. We even had the downstairs changed to include a downstairs bathroom, after he had his first transplant. All of the modifications added to his depression, due to the fact that the home had to be changed to accommodate him. The sofa bed was hardly comfortable to sleep on, but that became the place Dad could stay in as he could not get upstairs to his bedroom.

18. Despite his condition, Dad never viewed himself as disabled. Therefore, receiving a blue disabled badge was another trigger for

depression. Everything started to become a trigger for him, so he became more insular and a recluse. I recall him throwing his dinner plate at the wall one evening, out of anger and depression.

19. Dad was extremely fatigued and tired all the time. This led to family holidays being cancelled or, if he felt well enough to go, he would spend most of his time in the hotel room. The same would happen with family events.

20. In direct consequence of illness throughout the years, my dad was unable to have any more children. I am an only child.

21. He was left with no immune system after the liver transplant in 2002. The cirrhosis came back, and fibrosis of the liver started to form. Even a common cold would be like full-blown flu, lasting for a minimum of two weeks. His feet were also covered in warts, because his body could not fight against them. I remember that during his final year, he was confined to the living room for a few months. He could not put weight on his feet because it was so painful – the joints in his ankles seized up, so even when he felt well enough to possibly go outside, he was unable to. He was trapped 24/7.

22. From 2010 the varices in his oesophagus started to rupture, causing the stomach to fill with blood, which he would cough up. This lead to endless endoscopes and hospitalisations lasting for a week on average.

23. Dad was instructed to drink 5 litres of water a day and was given lactulose to flush the toxins out of the liver. His stomach ballooned and tripled in size, so it would have to be regularly drained.

24. His body was completely out of whack by 2011. He lost a lot of weight, was gaunt and he had jaundice. This all stemmed from the

liver not working properly. He ended up on 12 tablets a day and his body could not take anymore.

25. Towards the end, Dad suffered with hepatic encephalopathy and for the last year of his life could not be left alone. I recall him thinking that the front porch was the kitchen, and he had no idea where he was and did not know who Mum or I was.

26. It could be described as caring for a dementia patient. You are dealing with someone who through no fault of his own gets aggressive and confused. There would be times when dad would empty his bowels thinking that he was in the bathroom. He could not remember such events, so we started to record him. This was particularly distressing for him to watch. Due to the onset of hepatic encephalopathy, we decided to move dad's living arrangements downstairs and purchased a new sofa bed.

27. Dad was always freckly, but post-2007 he started to notice more moles appearing. This developed into severe skin cancer on his face, which spread to his head, along with patches of Bowens' disease on his back and leg.

28. In 2010 he started cancer treatment. The tumours were cut out and a freeze therapy was used for the Bowen's disease. There was a small tumour on his face, but half of his cheek was cut out to remove it. This had a real mental affect and emotionally scarred him. From my perspective, this affected him more than anything. By losing half of his face he felt he had lost his identity. Up until now his illnesses had been on the inside, but this was visible. He never wanted to go out even when he had the energy to do so.

29. Dad was diagnosed with diabetes in 2012, yet his eyesight had deteriorated previously. He had very cloudy vision and would get

thirsty often, both classic symptoms of diabetes. He tried to control the condition through his diet, but he still required insulin.

30. He had no teeth in the end due to extreme tooth decay. On one occasion in 2013, 3 teeth were extracted from the back and one from the side.

31. In 2000 he was placed on course of treatment including interferon but it had no success. He was placed on a waiting list for a liver transplant. He was on the list for two months, and had his first transplant in August 2002. Initially he was told that it would last 10 years, but it in fact lasted 12.

32. As the liver rejected twice and his Tacrolimus dosage increased, the hospital felt he needed to clear HCV as soon as possible. Dad was placed on a 24-week course of interferon and ribavirin to clear the infection. He had to be taken off the programme after 6 weeks; he was hospitalised with fatigue because his body could not handle the medication, and in general his body did not cope well this the treatment.

33. Dad had another unsuccessful attempt to clear the HCV in 2005. He reacted badly to the treatment; his skin bubbled and fell off in that area. This left permanent scarring. He tried again in 2011 but had the same reaction.

34. I recall being on holiday with friend in 2013 and before I left, Dad had been told he had cleared HCV following a year of treatment. My parents did not contact me for the whole week. I immediately thought something had happened, and in fact the HCV had come back.

35. At the end of 2012 he started another course of treatment, to clear the infection before a second liver transplant. It cleared after 24 weeks, but came back within a month. After an additional 24 weeks of the medication the virus cleared again, but he became very ill 16 weeks later.

36. The rounds of treatment were meant to be 18 weeks, but the hospital decided to extend the length in hope of a greater success. At this point he only had a year life expectancy, so they intended to put him on the list for a liver transplant once the virus had cleared. After he had passed away the doctors report stated that they could have had better success, if they had given a liver transplant first and then proceeded to clear the HCV.

37. In the end he was too ill for the transplant, as the condition of his liver did not improve. During November 2014 he was put in an intensive care ward. He came home for one day in December, but was readmitted the next day. Back in hospital he was placed on a ventilator and passed away on the 8th January 2015. GRO-C GRO-C

38. On his death records, it was noted that he still had traces of the virus in his system. It was never confirmed to us whether this meant the HCV had come back or it never cleared in the first place.

39. He had no difficulty in accessing treatment. Most was given on compassionate grounds and on the condition of being a case study for a very ill Stage 2 patient. I feel that the second transplant should have been given before, as his body could not cope with the intensive rounds of treatment.

40. 9 times out of 10 all medical appointments were in the afternoon. All of his dental treatment had to be through the NHS and via the hospital. The wait times for appointments were much longer, and

teeth would just be extracted rather than carrying out root canal, or bonding crowns onto the tooth. I would describe the dental care my dad received as always being basic.

41. Our whole living situation became more stressful than the average household because of all the medical complications brought on by the HCV. Going on holiday was particularly stressful, and would be ridiculously expensive due to the insurance premium. As a family we could not get normal travel insurance due to the HCV; it would be an additional £400 just for his insurance.

42. I would not say my parents' relationship was affected by dad's HCV infection, but it certainly made the family situation more stressful overall. Mum and I were his only social interactions in the end, as he did not see any extended family or friends. Dad found sitting at home having his wife and daughter care for him difficult; he had no quality of life towards the end. He lost everything he loved, including his car and being able to drive. He lost his job in a company that he worked for over 30 years, he finally reached the position of Managing Director, and had had it taken away less than two years later.

43. My grandparents felt guilty and responsible for his death, because they were the ones administering the blood products.

44. I had a unique relationship with my dad because we were so similar in character. Although we were very close, the relationship was intense. I feel this was all down to the fact that he was aware he would not be around much longer, which made him angrier about life.

45. When I was younger I assumed everyone's dad was as ill as mine and that children would care for their parents. It was drilled into me from a young age to keep everything clean, and to leave dad alone if he was tired. I still find it hard to differentiate my upbringing from what

is considered normal. Yes, I slept less and heard more arguments, but to me that was normal family life.

46. At the time I never classed myself as a career, but looking back I probably was. From the age of 15 I accompanied dad to all of his medical appointments, and from the age of 17 would drive him places. This was the reason why I learned to drive so quickly. I would come home from sixth form college at lunchtime to look after him, as mum was still working on reduced hours. I did the household cooking, would organise dad's tablets, administer his diabetes injections and collect all prescriptions.

47. Looking after my dad certainly affected my social life. I had no spare time after school, and every weekend I would be at home caring for him. On the rare occasions when he had energy, I would prioritise taking him out to enjoy some quality of life, rather than seeing friends.

48. My friends were cut out when Dad became ill. They just assumed he had a cold or something of the like, and never knew the extent of what I was going through.

49. My father's infection with HCV has changed so many aspects of my life. I suffer with depression and I had to experience losing a parent at a young age. He passed away over Christmas, so it makes the festive period even harder to get through. I do not celebrate my birthday anymore.

50. From the age of 13 I have dealt with depression myself, a downward spiral brought on thinking my dad was going to die. It got progressively worse, to the extent that I had to take time off school and regularly visit the school counsellor. She was a great help and would relay information to the teachers. At one point she was concerned I was at risk, so made a referral to a psychiatrist. During

this appointment, the psychiatrist said I was fine and that I was just a 'spoilt child'.

51. Even now I go to the doctors for depression and self-harm, but they see me walk in with a smile and say I am too positive about the day to be depressed.

52. Having to support Dad at home, along with going to school, working part time and dealing with other stresses was a lot to deal with. I was extremely tired of everything I was doing at the time, and from 2013 until dad passed away I did not sleep properly. He was constantly up in the night, and would require care 24 hours a day. It is physically exhausting looking after someone, especially when you are lifting a 6ft man.

53. Since his death, the relationship with my grandparents has deteriorated. I have not only lost my dad, but also the family from his side.

54. Dad was so ashamed by his HCV infection and did not want anyone to know. He pushed through setbacks to succeed in his career, so did not want his HCV status to jeopardise it. Apart from both sets of my grandparents, no one knows about the HCV.

55. As a child I was never told of dad's HCV status, but I always suspected something was there. My parents taught me from an early age to be clean and if I cut myself to always clean it and put a plaster over the blood. When I was 14, they informed me of the HCV but went on to say it had cleared. This was not true.

56. I can understand why they came to this decision, in case I told someone by mistake, but I would have been more prepared if I had known at a younger age. They were concerned about the stigma of the virus, and thought others would view us as dirty.

57. Around the age of 14 I recall having an argument with my dad, and being told that the HCV treatment had not worked. I think it was hard for him to keep it from me and it just came out in anger. I found this news extremely upsetting, as I thought he was already clear of the virus, but it put his tiredness and stress into perspective. We talked about it again a couple of weeks later.

58. Everyone around me assumed Dad was an alcoholic because of his liver transplant, and that I came from a broken home. I felt unable to correct them due to the complexity of how he was infected with HCV. If I did, they would only assume he was a drug taker and shared needles.

59. There was no impact on my education at secondary school and my GCSE grades were unaffected. At this point dad was at his 'normal' level of being unwell. When it came to decide what sixth form college to go to, I ended up staying at the one attached to my secondary school. As it was only round the corner from our home, it was the easy option to stay.

60. No one knew what our family was going through until my last year of sixth form, when dad's health deteriorated. I would often miss two periods each day to come home at lunch and at one point I was almost kicked out. This led us to explain the reason for my poor attendance, and I was allowed to come in slightly later.

61. I had a breakdown in my AS-Level Biology exam. One of the questions was all about the liver and it triggered me. I could not answer it and came out with a low overall grade. I was unable to carry the subject on because I had no time to re-sit the paper. I also ended up dropping physics, as there was no point carrying on one science subject. Biology fascinated me, so my intention was always to take a degree in the subject and become a researcher.

62. I felt everything that happened was normal, and I still now cannot understand how other people do not have to go through what I did. Considering the extent of the care I gave to dad, it was not a surprise my career path changed. I do wish that exam had not been about the liver, and I could have studied biology further, but I was still restricted by my caring responsibilities. I missed so much education during sixth form due to how ill he was, and decided only to pursue subjects that would not trigger me.

63. I missed the start of university when everyone forms their social bonds, so only made two close friendships. I never had the full university experience and attended for the course only.

64. Dad pushed for me to go to university as he wanted to see me accomplish something before he passed away. I decided to pursue a performing arts degree, so had a number of auditions. Bath University offered an unconditional place, but was too far away from home to accept. I knew there was no possibility I could go because of the amount of caring I was doing. I needed to be within 1 hour of the Royal Free Hospital and that narrowed down the options available to me.

65. Through clearing I got a place at Buckinghamshire University. I started in the autumn of 2014 and graduated in 2017.

66. I was in my first year when Dad became very unwell. As the grades did not contribute to my overall degree, it was easy to come home. Initially I started to commute, but this became difficult after breaking my foot in October 2014. Dad was admitted into hospital in November and died in January, so I remained at home during that period. I consequently missed a chunk of the course, and was penalised for having so much time off.

67. There was a huge impact on dad's career. He worked extremely hard to become a managing director of an engineering company, within the space of 10 years. His infection with HCV meant he was only in the position for 6 months. He never took a day off sick, and continued to work longer than he should have. Along with his job and pay cheque, he lost his company car.

68. Mum initially worked full time in a bank, but took a step back in her career as dad progressed in his. When he could no longer continue working, she took on more hours but never went back to full time due to the care he required. By this point she was working at a school on a basic salary. In effect we lost a whole income but only gained a quarter. All of the family savings were used for living expenses. Mum was not entitled to a widow's pension because he died too young.

69. I had no choice but to start work as soon as I was 16. Everything I needed I had to pay for myself. I was never told that I should pay rent, but I felt compelled to contribute to the household.

70. I was not entitled to a maintenance grant at university due to the fact that it was based on annual household income from the previous year. During the previous year, our household income had been much higher. The changes in circumstances were not taken into account. Consequently, all my living costs had to come from what I earnt part time.

Section 6. Treatment/Care/Support

71. To my knowledge, dad never faced difficulties or obstacles in obtaining treatment in consequences of being infected with HCV.

72. My parents were only offered counselling through the Skipton Fund but they never took it up. Dad was a very strong character, so it was

unlikely he would seek help and support. To admit he was broken would have broken him more.

73. Nevertheless, counselling should have been offered by the NHS and towards the end an appointment with a psychiatrist. It should have been the haemophilia department who arranged this. Mental health workers do not know enough about the contaminated blood scandal to give adequate support.

74. The Inquiry Team informed me about some work they are doing with the British Red Cross. I was given a card with some contact details on it and was advised that I can call a support line arranged with the British Red Cross should I need to talk to someone.

75. I was never offered any support from the medical profession. It should have been assessed at the start, the mental health implications arising from my dad's condition. Instead I was dismissed as fine. No one realised the effects it can have on the whole family.

Section 7. Financial Assistance

76. I remember that my parents received financial assistance from the Skipton Fund and the Caxton Foundation, but I am unsure of the amounts given or when the payments started.

77. As well as discretionary payments, my mum also received an amount to cover funeral costs.

78. We continue to have the winter fuel allowance, but it does not cover the entire cost of gas and electricity used.

79. Due to his condition, dad had to apply for benefits in the end. For a man who had always worked hard this was difficult, and acted as another trigger for his depression and stress. It was demoralising to

receive benefits when there are funds specifically for those in his situation.

80. I applied to the Caxton Foundation for support when my student finance was disrupted. They stated there was a precondition to go through all of the government benefit schemes before seeking their help. The process was distressing and took 6 months overall, by which point my father had passed away. I was still paying for student accommodation, despite not living there nor being able to work with my broken foot. I received nothing for the first year.

81. I had to go through everything again in August 2015, for the next academic year. I was granted £200 for every month at university. This was only enough to cover two weeks of rent a month. In total I had to apply for financial assistance three times. Student finance covered the cost of the tuition fees.

Section 8. Other Issues

82. I decided to focus on contaminated blood for a performance piece at university in 2017 titled 'Tainted Blood'. This involved research into previous inquiries and comparing payment schemes of different countries. All the information was consolidated into a one-person performance.

83. I got a good grade and was selected to do a showcase. The show toured for two weeks in London between March and June. I felt it was selected because there was interest around the topic and there was little awareness. Approximately 14 people were informed, and one woman was from St Bart's Health.

84. When I fractured my foot I spoke with a paramedic about the infected blood scandal while I was in the ambulance. Astonishingly she implied it was not true and said my dad was probably infected from sharing

needles. It seems as though NHS workers do no want to hear negative comments about the organisation, especially as they are struggling at the moment.

85. From personal experience, there seems to be a lack of awareness that the NHS using infected blood. For those that do know, as it was so long ago, they do not care.

86. No amount of money can put a price on my dad's life. A detailed apology would mean more to me than money, but obviously money will help to make our lives easier now. I understand that everyone goes through financial struggles, but ours stem directly from dad being infected with HCV. Our lives would have all been so different if he had not been given Factor VIII. I want everyone to realise that my dad did not have life insurance because of HCV, and this put a huge financial pressure on our family. My dad had to deal with the fact that he could leave nothing behind for his family. My mum does not receive a widow's pension, as Dad died to young and of HCV, despite the fact that he paid into his state pension for 30 years.

87. I felt that the apology from David Cameron was rubbish, and there are still so many answered questions. I want to know why 'contaminate' was written all over my dad's medical records within a year of being given Factor VIII, but why he was not told of his infection until years later.

88. It needs to be recognised that individuals are liable for this, and the whole scandal could have gone away sooner if it had been addressed correctly. In so many other countries this has been the case.

Statement of Truth

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

Signed GRO-C

Dated 10/06/19