Witness Name: Elaine Feterston
Statement No.: WITN7657001
Exhibits: **WITN7657002 - 003**
Dated: 08 March 2023

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF ELAINE FETERSTON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 28th February 2023.

I, Elaine Feterston, will say as follows: -

Section 1. Introduction

1. My name is Elaine Feterston. My date of birth is GRO-C 1960 and my address is GRO-C Liverpool.

2. I have worked as an administrator for the Liverpool Drug and Alcohol Service for 32 years. I have been on sick leave for the last year owing to illness with COPD and emphysema. I was recently told by my doctor that I am no longer fit to work and I will retire due to ill health this very week.

3. I live alone. I have one daughter aged 38, who lives locally and I have two grandchildren, a boy and a girl.

4. I intend to speak about Kevin Feterston, my late brother and only sibling. Kevin was infected with HIV through receiving infected blood products, and died from AIDS aged just 27 in 1988. I intend to discuss Kevin's haemophilia treatment, his illness with HIV and AIDS, how the illness affected him, his premature death and the impact this all had on him, our mother and myself.

5. I should say that much of what happened with Kevin was not in my direct knowledge, as I was either too young when we were growing up or I was dealing with bringing up my baby alone when he became ill. I am the only family member left, who can tell Kevin's tragic story and much of what I will say in this statement will be what I was told, mainly by my late mother.

6. The anonymity process has been explained to me and I am happy for my name to remain on my statement.

Section 2. How Affected

7. Kevin was born on GRO-C 1961, exactly one year to the day after me. When he was 6 months old, Kevin was diagnosed as a severe haemophiliac. Mum told me that he bruised easily and would often swell up, which led to Kevin being tested. Mum had no idea that haemophilia was in the family. Much later, when I was 16, I was also diagnosed as being a haemophilia carrier.

8. Kevin was in and out of hospital throughout his childhood. As I recall, Kevin used to go to hospital to receive clotting transfusions on a regular basis. He was a boisterous toddler who enjoyed what all other boys did, playing, climbing and jumping off things.

9. These activities would inevitably result in Kevin needing to go to hospital to treat an internal bleed. It was usual for Kevin to remain in hospital for one or two weeks. This was just the norm for him and me throughout our childhood. I can remember often seeing an ambulance pull up outside

our house as I watched from the school classroom over the road. As I remember, his joint bleeds were the worst and caused him the most pain.

10. Kevin's haemophilia treatment was under the care of Alder Hey Children's Hospital haemophilia centre until he was 15. At that age, he then moved to be under the care of the Royal Liverpool Hospital.

11. It is my understanding that Kevin received 'clotting transfusions' during these years, throughout the 1960s and possibly early 1970s. I have since learnt that these transfusions were called cryoprecipitate, administered in hospital intravenously from a frozen bag of plasma.

12. Kevin was admitted in to Lord Mayor Treloar's School when he was about 11. This was around the time our parents divorced, our father having moved to Swansea when I was 8 years old and Kevin was 7.

13. I think it was that Mum was struggling to cope with Kevin's ongoing need for regular clotting treatment and his disrupted education, which led to his admission to Treloar's, where haemophilia could be easily and locally treated. He was there for 3 years or so. I have no idea what Kevin's experience of Treloar's was like, nor how often he received haemophilia treatment there.

14. Mum and I used to visit him at Treloar's from time to time. I was just a year old older than Kevin so my memory is very vague. I do recall that the school felt enormous to me. I knew it to be a boarding school and I can remember he was in a dormitory with other children. I cannot say whether he was in a group of other haemophiliacs. He did make friends with a thalidomide child, whose mother our Mum also befriended. He also grew close to a girl in a wheelchair.

15. Kevin was expelled from Treloar's when he was about 14 after he pushed a teacher into the swimming pool. After this, Kevin came home and attended a special school called Springfields. His level of education was poor due to all the disruptions. In today's language he would probably be considered to have learning difficulties.

16. Kevin's teenage years were mostly spent on his own in isolation. He left school aged 15 or 16 and became a hermit. I believe his haemophilia to have been in a factor in this, mainly because he felt different and singled out compared to other boys his age.

17. Around 1982, when he was aged 21, Kevin went to live in GRO-C. Our cousin was working down there and offered him a bed in his flat. Kevin grasped the opportunity and we were all delighted for him. He did some menial work while there, the only work he ever did. We thought it would do him good to get away from home and be out more, which proved to be the case.

18. Kevin's time in GRO-C was the happiest time of his life. He grew out of his shell and was a completely different person. I saw a much happier, open and contented side to him that I had never seen before. Maybe Mum had wrapped him up in cotton wool too much and he needed the space to flourish.

19. Kevin was in GRO-C for about 3 years, from 1982 to 1985. At some point in 1985, Kevin had a bleed in GRO-C. He phoned an ambulance and told Mum that all the paramedics had arrived in masks and gowns. This didn't really register with me at the time, and I didn't read any more into it. It later became obvious why this was.

20. After this episode, Mum persuaded Kevin to return home. This was the same year that I had my baby daughter, Beth. I was completely occupied with caring for her and so my memory of this time is very vague.

21. I think I first learnt of Kevin's HIV diagnosis in 1986. I don't have a clear recollection of how this was conveyed to me, although I suspect that it was Mum who told me. I was oblivious to everything surrounding HIV/AIDS at the time. I was completely ignorant of what was going on in the news on the TV and in the papers.

22. I certainly cannot remember having an understanding of the significance of what this meant for Kevin. I think it was my aunt, my mother's sister, who was a nurse and who properly informed us what HIV/AIDS meant.

23. In preparation for providing this statement, I have been going through what I have of Mum's old correspondence and documentation regarding Kevin. I found a letter that Kevin wrote to my uncle. Kevin wrote the handwritten letter, dated 21st June 1985 and attached as exhibit **WITN7657002**, whilst he was in GRO-C. Kevin explained that he had recently been admitted to Torbay Hospital for a week with a "bad knee". He then wrote that "whilst I was there, Dr GRO-D (who is the Consultant) told me that the blood test he took showed that I was carrying the AIDS virus. Obviously as you can expect, I just went sick when he told me that."

24. Kevin continued: "But life goes on, and if there is such thing as a BRIGHT SIDE, after news like that, it's that he reckons himself that since I've been down south for at least 2½ years, it had to have been before that. The reason being, that all the time I've been down here, I've had the pure Factor 8 which is Cryo-precipitate. Not the bottled stuff which is supposed to be the culprit, and which I last had at least 3 years ago when I was in Liverpool."

25. Kevin later wrote that "… I haven't told my mother this because she's got enough problems of her own, with her illness at the moment and I think this news would be the last straw. So this will be between me you and my dad, or at least while it is dormant in me."

26. I have only recently discovered this letter, I had never seen it before. It explains why Mum, and by extension myself, was not made aware of Kevin's HIV infection until 1986. I cannot say for sure but this may be because the 'AIDS virus' was no longer dormant in Kevin by 1986.

27. It is also a good indicator that Kevin's HIV infection was almost certainly contracted before he went to GRO-C and as a result of factor VIII

treatment that he had received from the Royal Liverpool Hospital or maybe even earlier at Treloars.

28. After I became aware of Kevin's HIV status, my aunt began to educate us all on the potential risks of transmission. At the time we knew very little about it, and no information had been provided to us. We were warned to avoid sharing toothbrushes and glasses. I remember being careful in keeping my daughter well out of the way if Kevin had a bleed.

29. After Kevin's diagnosis and with him living again with Mum, he went back to square one, preferring to isolate himself in his bedroom again. Despite Kevin's diagnosis, me, Mum, and our friends all endeavoured to normalise Kevin's life. We never treated him any differently. We had all taken it upon ourselves to learn more about it. Even so, I think that I knew then that Kevin was going to die of AIDS.

30. In either late 1986 or early 1987, Kevin had a fall on the stairs. He was walking upstairs with a portable TV when he fell and landed at the bottom. By this time, Kevin was becoming thin and weak. He couldn't move at the bottom of the stairs and Mum phoned an ambulance.

31. When the ambulance arrived, the paramedics thought the spleen could be damaged. They said if that was the case, they didn't have time to get him to Royal Liverpool Hospital and took him to Walton Hospital for an emergency surgery to remove the ruptured spleen. Blood products had to be delivered there from Royal Liverpool.

32. The next day, I went to visit Kevin with Mum. I had to wear a mask, gown and gloves to enter the room, and the entrance to the room had a prominent sign on it warning that Kevin was an 'infection risk' or something similar.

33. My auntie was also there and told us that she had to clean the room before we got there because it was covered in swabs, plasters and bandages. She had made a complaint to the hospital about this before we arrived.

34. The next day, I returned to visit Kevin with Mum and the room was disgusting again. My auntie said this was unacceptable and again made a complaint to the hospital. When she did so, she was told that one of the cleaners had learnt of Kevin's HIV status and had refused to clean his room, presumably the rest of the cleaning staff followed suit. I was heartbroken by the state of the room. I was disgusted that no one would clean it except his own family.

35. We subsequently became aware that the press had found out about an AIDS patient being in Walton Hospital and published this in the papers. Kevin's name was not given but it was very upsetting nevertheless.

36. Kevin was in hospital for 6 weeks after his spleen was removed. When he got home, his health went into a rapid decline. He was growing increasingly frail and weak. He lost a lot of weight and his face appeared gaunt. He also became incontinent.

37. Although Kevin was on some sort of medication, the name of which I cannot recall, there seemed to be nothing anyone could do to prevent his rapidly deteriorating health. Kevin was admitted to Royal Liverpool Hospital about 3 weeks before he passed. We all knew that he was dying.

38. On the day he died, 6th December 1988, Kevin fell off the commode in hospital. This was the final straw for him and Kevin died shortly afterwards. He was just 27 years old.

39. Kevin's death certificate did record that he had AIDS. I also believe haemophilia was recorded. I remember this well because my father complained about it. He was insistent that Kevin's primary cause of death be recorded as haemophilia because he believed that the haemophilia was what had led to him being infected with HIV/AIDS. I don't think he won the argument and the death certificate was left unchanged. My father's view was that he did not want people to think

that Kevin was gay. Those were the times we lived in. I have not been able to find Kevin's death certificate.

40. After Kevin died, the undertakers refused to embalm Kevin's body. This was another very upsetting incident at such a difficult time for us all.

Section 3. Other Infections

41. I am unable to say for certain whether Kevin was also infected with hepatitis C ("HCV") although I believe he most probably was, knowing what I know now about infected blood products.

Section 4. Consent

42. I was too young at the time to have been informed as to any issues regarding consenting to treatment or testing that Kevin received.

43. I am unable to say whether Kevin and/or our mother was informed about the risks of infected blood products. I do think it is doubtful that they were ever informed.

44. As far as I am aware, Mum was not consulted to consent for treatment that Kevin received at Treloar's, although she may have given some kind of 'blanket' consent when he first went there. Consent may have been implied by her agreeing for him to go there, I just don't know. However, if that was the case, I have no idea whether that would serve as proper consent.

45. I do not believe that Kevin was told that he was being tested for HIV. This is supported by the letter that Kevin wrote to his uncle (**WITN7657002**) in which it seems that his HIV diagnosis came as a total shock following a routine blood test at Torbay Hospital under the care of Dr GRO-D.

Section 5. Impact

46. Kevin's death devastated Mum. She was distraught at having lost her child. After his death, Mum went to the bedroom and stayed there. She only ever got up to make dinner for when I got home from work but she would put this on the table and go back to bed.

47. Mum entered a prolonged period of mourning that developed into a state of depression. She gave up and lost the will to live. Her life was her bedroom. All she did for two years was watch TV and do crosswords in bed. She lost her sense of purpose after Kevin died.

48. I sold my house over the road from Mum after Kevin died and moved back in with her and my daughter. I effectively became her carer.

49. When I was pregnant, in 1984, I had to check the baby's gender because I was terrified that I would pass the haemophilia gene onto my child if it was a boy. I had seen what Kevin's haemophilia had done to his life, and the impact this had on him and our mother. I was worried the whole thing would be revisited again if I had a boy. Thankfully it was a girl GRO-C GRO-C.

50. My daughter lost the early years of bonding with her grandmother because my Mum was so shattered by the loss of Kevin. She barely interacted with her granddaughter for the first few years, although thankfully she made up for this in later years before she passed away.

51. Even though Mum began to live her life again after a few years of grieving, she was never the same person after what happened to Kevin. Mum died of cancer in March 2010 aged 71.

52. Kevin's health decline towards the end was heart-breaking to see. He was incredibly brave. I think he just accepted his diagnosis and saw it as

just another illness. He was used to being ill and he treated it as just another illness connected with his haemophilia.

53. I know now that Kevin should never have been infected with HIV. Who knows what sort of life he could have had. I think back to how happy he was living and working in GRO-D, only to then be handed a death sentence at a routine hospital visit for his haemophilia. It is harrowing to think about.

54. I feel a lot of anger and resentment towards the Royal Liverpool Hospital and/or Treloars, for giving Kevin factor VIII infected with HIV. I am angry towards the government, who knew what was going on and could have and definitely should have prevented so many people from dying, once they knew there was a problem with imported blood and blood products.

55. Kevin had a great relationship with the consultant at Royal Liverpool, unfortunately I cannot recall his name. Kevin used to tell him that he had no idea how much pain he was in, and the consultant agreed with him. He was an understanding and sympathetic doctor but this does not alter the fact that he gave my brother HIV through infected blood products.

56. Having witnessed the stigma that Kevin was subjected to even by hospital staff and cleaners, we kept Kevin's HIV status solely amongst family and close friends. There was a great deal of misinformation and ignorance surrounding HIV/AIDS and regrettably this resulted in fear of those infected. Even some family members stopped coming to visit Mum's house after Kevin's diagnosis. Thankfully my friends were understanding and they never judged Kevin.

Section 6. Treatment/Care/Support

57. I am not aware that Kevin faced any difficulties in obtaining treatment, care or support in consequence of his HIV infection. He was certainly

treated as an infection risk by medics and at hospitals, but to my knowledge, the treatment itself was not affected because of this.

58. Counselling or psychological support was never offered to Kevin in respect of his HIV infection, nor was it offered to my mother or me in respect of Kevin's HIV diagnosis or his death.

59. Having been asked this, I wonder whether my mother would have benefitted from being able to speak to someone. It may not have helped, but it definitely ought to have been offered to her after the trauma she had been through. For a parent to lose a child is unbearably heart wrenching and she had no help from anyone. The possibility of counselling or indeed any sort of support was never even considered or discussed.

Section 7. Financial Assistance

60. After Kevin's death, I believe Mum was involved in some way with the Macfarlane Trust. I am aware that she was in correspondence with them, having found documentation evidencing this, however I cannot say whether she received any form of payment from them. One of the documents from the Macfarlane Trust implies that a payment may have been due to be paid but no mention of an amount is made and there is no evidence of confirmation, so I cannot be certain.

61. I have a letter from J. Keith Park & Co Solicitors to my mother dated 25th June 1991 (attached as exhibit **WITN7657003**) that refers to an enclosed cheque in the sum of £23,500. In the last paragraph of this letter, reading 'It has been a stressful and harrowing period of your lives been [sic] involved in this litigation', which indicates that this payment was made pursuant to a claim made through court proceedings and possibly a group action. I am not aware that my mother was ever involved in a group action or legal case of any kind. However, if she was, she certainly would not have instigated this herself. To my mind, she would have had to have

been contacted by either another party or the law firm dealing with the litigation.

62. I remember Mum receiving this payment. She refused to spend the money herself, labelling it as 'blood money'. Towards the end of her life, I used the money for home improvements to my mother's house and for the purchase of a car.

Section 8. Other Issues

63. I feel devastated and sorrowful to everyone who has lost family or friends as a result of infected blood.

64. Haemophiliacs should have been informed of the risks of infected blood. Clinicians knew of the risks but decided not to inform haemophiliac patients. We were all completely ignorant of the risks.

Statement of Truth

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

Signed GRO-C

Dated 8/3/2023