Witness Name: Catherine Bailey
Statement No.: WITN108201
Exhibits:
Dated: [25th] September 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF CATHERINE BAILEY

I, Catherine Bailey, will say as follows:

Section 1: Introduction

1. My name is Catherine Bailey. My date of birth is GRO-C 1956 and I live at GRO-C I am employed as a landscape planner, I am separated and have a 22-year-old son GRO-C GRO-C

Section 2: How affected

2. I am the younger of two older sisters of brothers, John Magee and James Magee, both of whom had mild haemophilia A. As a result of their condition both of my brothers received blood products as part of their treatment at King's College Hospital in London. My brother John passed away on 19 June 1981, at the age of 21, following a short illness, before the risk of HIV and AIDS were in the public domain and my brother James died on the 5 February 1991, at the age of 27.

3. My brother John was born on GRO-C 1960. He suffered from dyslexia at a time when, while the condition was known about, it was not treated or managed. As a result, he was never brilliant academically, but was good-natured and something of a joker with an infectious giggle. John also suffered from eczema and asthma, and was sometimes bad tempered and irritating, but he could also be silly and fun.

While I found him challenging and annoying at times when growing up, we later became good friends.

4. My youngest brother James was born on the GRO-C 1964. He was very bright academically. My memory is as the youngest he had more of a forgiving upbringing than the rest of us, and my parents were less strict with him. My father had studied at Oxford (my mother was a doctor) and so, being the most academic of my siblings, James as the youngest child was important to him. He was always very easy to get along with and was wise beyond his years. I remember him writing me a letter once with advice and thoughts following a family argument. He would have only been 16 at the time.

5. As far as I can recall my parents were not aware of a history of haemophilia in my mother's family. I believe our first awareness was when my younger brother James, who was two years old at this time, fell down some steep steps we had in our garden and developed a large haematoma on his forehead that we jokingly called "*The Egg*". Despite the joking however my mother knew that this was unnatural, and it raised concerns for her. Following this James was diagnosed with mild haemophilia A. John was also found to have mild haemophilia A.

6. I cannot recall this diagnosis having significant impact upon them when they were young. I remember John swam and played tennis and James played some squash, so there were opportunities for incidents to occur but hardly ever happened. In connection with the litigation proceedings related to his HIV infection, ("Litigation"), in 1988, James prepared a detailed and moving statement ("Statement") in which he states that he played a little rugby in his early years **(WITN1082002)**, but I do not recall this. The proceedings are described in more detail below. I do not believe that my brothers changed their habits due to their medical condition, but rather just continued doing what they liked to do. We lived in London until 1979 when my brothers were in their teens, and then my parents moved to GRO-C.

7. There were very few incidents that I can remember which resulted in them needing treatment. In James's Statement he recalls that there had been only nine incidents in total which had required treatment (**WITN1082002**). I do remember that John

once hit himself on the head with a tennis racket while enthusiastically serving which caused swelling, something that made him look to the family like a Dr Who character.

8. I cannot recall in detail what treatments my brothers received and when. Given my mother's occupation, we always had faith in the medical profession, and didn't question their treatments. I do recall that they received Factor VIII concentrate, as they attended hospital for treatment, something we thought was extraordinary, in the way it gave them safety and security. They must have received cryoprecipitate prior to this, but as a family we had limited discussions about this. I believed, as my mother was a doctor, that the doctors treating my brothers knew best.

9. I have no memory as to whether or not my mum or my brothers were ever warned about any risks associated with the treatment that they received, although I know that my mother would know that no procedure was risk free, due to her profession. That being said, she was as surprised by the eventual outcome as anyone else and certainly would not have anticipated such a tragedy.

10. My brothers' conditions rarely affected family life, and we all had faith in the NHS and believed any treatment was helping James and John to live active and fulfilling lives. Going to see their haemophilia consultant was a normality, and not something they ever saw as a problem.

John's illness

11. By the time I went to university, John had moved out and was living with friends of our cousins in a flat in London. He would come home for Sunday lunches to see the family. He was working for Benn Brothers, the publishers, in sales.

12. In early 1981 John fell ill with a fever. He was ill for several weeks, and there was an assumption, after a while that it was glandular fever. Eventually he had to be taken into hospital. I had visited him in early June 1981, unaware that it was anything significant, other than a high temperature and fever. I remember joking with him about it by asking if I could have his hi-fi if he didn't recover.

13. I had moved away to study at the University of Newcastle, taking a Masters in landscape design at the age of 24. I received a message on the communal phone in my accommodation, asking for me to call home and assuring me it was nothing urgent. As it was rare to receive such a message, the phone call made me suspicious, and I assumed it was something to do with my grandmother. However, it was John. He had died suddenly on 19 June 1981, which came as a huge shock to me, as I had no idea at the time that he was seriously ill, despite the fact he had been in hospital for two or three weeks. We certainly had no idea that he had been infected by a virus as part of his treatment. His post mortem found that the cause of death was a bicuspid heart valve and endocarditis. While we were unaware of his infection, my recollection is that the hospital staff limited access to his room during his illness.

14. I do not know what medication was used to treat John during his illness, or if the doctors suspected anything other than glandular fever. My sister recalls that the GP did pick up a heart murmur and he was receiving antibiotics in hospital for bacterial endocarditis. Apparently, a healthy young person would have been expected to recover with this treatment and he did begin to improve, but then died the night before he was due to be transferred to Kings College Hospital for more specialist treatment. In retrospect he was probably immune-compromised by HIV.

James' illness

15. James had done well in school, and went on to study product design at Hull University where he secured a first-class degree. It was while he was there that he met his girlfriend GRO-C They were together throughout their time at university and stayed together for several years after.

16. After university, James had hoped to go to the Royal College of Art to study design, but unfortunately, he didn't get in. However, GRO-C secured a place at GRO-C GRO-C, so they bought a place together in GRO-C and James got a job in product design.

17. In around 1982 or 1983 AIDS began to enter the media, although there was no diagnostic test available at that time. In 1985 James was invited for testing by Pembury Hospital. By this time the doctors knew that the HIV was a blood borne virus, and we were told that they were testing all haemophiliacs as routine. I believe they told James why they were testing him and had his full consent to do so.

18. In James' Statement, he recalls that he was formally given his diagnosis of being HIV positive on 8 January 1986, having been infected by contaminated Factor VIII, although he implies he had been informally told in December 1985 (**WITN1082002).** I do not know what information he was given about managing his illness, or if any particular medications were offered.

19. James did not keep his infection a secret, and the rest of the family heard about the infection almost immediately from James himself or other family members. I remember my sister calling me with the news while I was working in Camden. We believed that it was a death sentence at that time. Despite this, his health at the time of diagnosis was fine, and he kept working for as long as possible.

20. Before his death, James' health deteriorated and he had to give up work and move down to Kent and eventually in with our parents so they could care for him in the last months of his life.

21. James died of HIV related illnesses on 5 February 1991 at the age of 27. His death certificate listed the causes of his death as bronchopneumonia, AIDS and haemophilia.

Learning of John's Infection

22. In 1991, following James' death, and as part of the ongoing legal case at that time, some of John's tissue was tested for HIV and Dr Henry Hambley of King's College Hospital informed us on 17 December 1991 that it had twice been found to be HIV positive (**WITN1082003**). This testing followed a request my father made as part of the Litigation process, which he continued after James' death. We were not surprised by the result, as by that time the contamination of blood products had become common knowledge, and we had no reason to hope John might have

avoided it. We have, however, always found it odd that John's tissue had been kept for so long after his death. My mother recalls that at no time prior to his death did my parents give active consent for my brother's tissues to be retained.

Section 3: Other Infections

23. I am not aware of either John or James suffering any other infections, aside from HIV, as a result of receiving infected blood products, but I cannot be sure if others were diagnosed as I have not yet seen their medical records.

Section 4: Consent

24. My understanding is that any testing James underwent was consensual. As I mentioned earlier, he was called into Pembury Hospital as they told him they were conducting routine checks on haemophiliacs who had received blood products. I do not know about any tests that John underwent when he was alive, however the post-mortem test for HIV was conducted with my parents' consent although my mother has no memory of consenting to the retention of tissue.

Section 5: Impact

Impact of John's Death

25. My elder brother John's death affected the family in many ways. My mother in particular had always been close to John as he could be fun and giggly. She entered into a coping mode to get through it. We were not the sort of family who talked about these things; we just tried to get on with it. We saw it as a tragedy that could have happened to anyone, as at that time we were not aware of the risk of infection posed by blood products.

26. My father seemed to delay his reaction to John's death until after James' death, and similarly tried to get on with it. He had been saddened that John was not academic like him, and I suspect he thought John was not very bright. I remember after John's death he once said "*John always struggled, maybe it's for the best*". I

think this bluntness was a generational response, a way of coping that was common among those who had lived through the war.

27. When I heard about John's death I took the train home, standing in the train corridor as there were no seats, and cried the whole way from Newcastle to GRO-C. When I arrived home, I tried to cope like the rest of my family. I felt that I had to carry on for James' sake, as he was my younger brother. As far as I am aware no-one in the family thought John's death was connected to his haemophilia. My sister was already settled down and married at this point, living in GRO-C London where we had grown up, but after the funeral I had to go back to university. Our family friends in London and GRO-C rallied round my parents, but as I was in Newcastle I had no forum in which to talk about what had happened.

28. While I had found John to be challenging at times as a brother, we had become friends in the last couple of years of his life. It has been hard for me as I have missed out on his friendship over most of my adult life. In retrospect, I believe that I would have stayed close to John had he lived, and this loss is hard to cope with.

Impact of James' Illness

29. James' diagnosis was understandably extremely difficult for him, and he writes movingly about it in his Statement **(WITN1082002),** even saying that he felt no elation about receiving a first from university. He became depressed and tried to distract himself from his diagnosis, continuing to work for as long as he could.

30. I do not recall him saying he ever suffered from stigma as a result of his diagnosis. As part of his work in product design he sometimes had to mock up items in wood or clay, and he once cut himself during this task, meaning he felt obliged to tell his supervisor about his infection due to the potential risk. I recall he asked his supervisor to keep this to himself, which I believe he did. As far as I'm aware he never faced any stigma or discrimination as a result of having HIV at work.

31. In fact, he appeared very open about his situation with his friends, and never to my knowledge faced any of the backlash or hate that has troubled others. He had lots of friends, mixing in an open, communicative and creative crowd, and I don't

believe he faced any stigma or lost any friends because of his diagnosis, maybe because of this demographic.

32. As for the family, it felt that we had the confidence to ignore the stigma and the scaremongering in the press about the illness and its transmission. I remember once using James' toothbrush as a small display of defiance against it. I knew that my mother would do whatever it took to try and help him.

33. As for how I coped with James' diagnosis, I felt I had to keep going, that I couldn't make a song and dance about it for James' sake. He was having a difficult time dealing with his diagnosis and I wanted to support him. I think I had some element of expectation that the medical world would somehow cure him, and inherent belief that his infection with HIV didn't have to be fatal. I was in denial in some sense. No one ever asked me how I was feeling about it, nor did I really know how to ask James how he was feeling. James and I did discuss it, but not a lot, as I didn't really have the words for it.

34. It was very hard watching James' health deteriorate. I remember going swimming with him at Tooting Lido. Even though he had always been a strong swimmer, I managed to swim ahead of him. He was beginning to slow down. He had no serious bleeds during this time that I can recall, with the exception of a bleed into his stomach which was due to stress in 1987, which he writes about in his Statement.

35. I do not know if the doctors or our mum had told James about the risk of transmitting HIV to his girlfriend, but he would have known about the risks from the media, and I am sure that he was aware of the risk. We did not discuss this however, as I was 30 years old at the time and neither of us would have wanted to discuss my brother's sex life.

36. James' infection meant that he and GRO-C were unable to try and have children, which was very upsetting for him, something he speaks about in his Statement. He writes that he was "*particularly angry that at present there seems to be no prospect of our having children as I would very much like a family of my own*" **(WITN1082002).** GRO-C

GRO-C

37. Sadly, the pressures of the infection became too much and James and GRO-C broke up. She wanted a family, and had been offered a research position in Manchester. Due to James having HIV, having a family was out of the question, at that time. As she could not have a family with James, GRO-C felt she had to leave. Apparently he said that splitting up with GRO-C was worse than being diagnosed with HIV. He had many friends, including girls, and although I thought that he did not have an intimate relationship with anyone again, my sister believes he did go out with an old female friend for a while.

40. Sometime after GRO-C left, James' health deteriorated. As a result, he had to move closer to home, so that our parents could look after him. They couldn't sell his flat in London, and when it was sold, half the value went to GRO-C. He couldn't get a new mortgage because he had HIV, so my father had to take out a second mortgage in order to support him. This caused my parents some financial troubles. In a letter to the MacFarlane Trust, my father noted that "*James has left his mother and father all his worldly possessions – and also a considerable financial problem*" **(WITN1082004)**. Everyone rallied around James, and one old school friend even moved from Edinburgh into James' new flat and helped to look after him.

38. James was put on AZT before he became very ill. We understood this to be something of a wonder drug. His appearance didn't really change until the final few months of his life, but I think he suffered from side effects from these drugs although I cannot remember what they were. My sister recalls that he was treated with AZT although he was asymptomatic. He returned from a trip to Australia complaining of muscle weakness and wastage and my sister always wondered whether the toxicity of the drug was affecting his health more than the HIV.

39. In the last few months of his life James moved back in with our parents. He was given a liver biopsy late in 1990, and my memory is that after this he could not speak properly. My mother does not remember this but says he appeared to develop a form of dementia which she assumed was the effect of the virus on his brain. I recall by the time of his final birthday he was not able to communicate properly. His speech would become muddled, and he used to struggle to express the words that he was searching for. I found it very difficult to watch him lose the

ability to communicate following this procedure. My mother remains suspicious as to why he was given the biopsy and recalls that due to his haemophilia he suffered some bleeding. She stayed with him in the hospital and queried the doctors as to why they had done the procedure. In retrospect, we suspect the doctors looking for signs of Hepatitis C infection.

40. By the time of his last birthday, his physical health had deteriorated drastically and he had become very gaunt and skeletal. I remember that he looked old. He couldn't eat or drink properly, and was having to drink a protein mix through a straw. All of his friends had come around for a party, and we took some photos of the celebrations, although I have not seen them since they were first printed. I do not think that I would want to see them now.

41. In the last few weeks before he died James was confined to a bedroom upstairs at my parents' house.

Impact of James' death

42. When James died, my father seemed to breakdown. He had never been an emotive man but I think James' death triggered feelings and grief repressed since John had died. He changed markedly, and became like a different person as far as I was concerned. He had always been a social drinker, but after James' death he started sitting by himself in a dark room, drinking and listening to mournful music.

43. My father and James might not have shared feelings, but they shared traits and interests. James was academically bright like him, and they both liked art, my father having been an amateur watercolourist. Once, in the late 1990's I found my father going through James' old design portfolio, and weeping heavily; I think he might have been drunk. He pushed the portfolio at me and told me to "*take this, and look after it, James was so fantastic.*" He took solace in his garden. I think my father was very affected by having to give up his aspirations for his sons.

44. In the years running up to James' death, my father threw himself into helping James with the Litigation and he continued this after James died. I think this was

his way of coping, his way of being able to do something to help. I knew he was involved, but we never had in depth conversations about it at the time.

45. As she had done previously following John's death, my mother had to carry on. She was the focus of the family, and so when friends or family came to comfort us, it was she who received their full support. They were always being invited out to visit or stay with friends, but I think this was a distraction. They were always out of the house and because of this I don't think they ever had the chance to grieve privately. James' death has had a lasting impact upon me. I was only 34 at the time of his death and had been in a relationship for eight years. As James' care changed from treatment to palliative care my boyfriend left, I think because my focus was on my brother and wider family not on his wellbeing. When James died, I thought that the best way for me to help my parents was to try and just keep going, even if that was emotionally stressful and lonely

46. Later, when I had married, I wanted to support my parents, but this was made difficult by distance, as I lived at a distance in GRO-C I feel that I was outside of the support network, just like I was after John had died. I have remained living in GRO-C due to personal circumstances; the distance from my family has not been by choice. Just because I am further away does not mean I haven't been as affected, or that I haven't wanted to participate in family life.

47. The loss of my brothers has had an ongoing impact on me, and I believe other relationships have suffered as a result. Quite recently my husband left me, and I think that the breakdown of our marriage was an indirect result of my need to share the pain of my brothers' deaths and the support that I needed following these experiences. My father was diagnosed with dementia in his mid-70s, and the geographical distance between my parents and me felt greater, as it was not easy to be there to visit him. My father died in 2012 and my mother is now 92 years old and still living on her own.

48. My brothers' deaths have also had a lasting impact on how I see risk, and I am now constantly on edge. I assume that every late night phone call is bringing bad news or that something terrible has happened if I have not heard from someone

when I expected. I can see that I am perhaps not the easiest person to be around, or the easiest parent for my son.

49. I have had to keep rebuilding my life, after John's death, after James' death and again after losing my father. Circumstances have meant I have often relocated or moved job so I have had to decide how much to tell people about having lost two brothers or if I should mention them at all. It has been very draining sometimes.

50. The new generation of the family have brought my brothers' lives into the present. We talk about them on occasion, and try to keep their memory alive, but we want to have fun with the current generation as well rather than dwell on the past. However, when we are together as a family, the memory of my brothers is ever present and their absence looms large in the room.

Section 6: Treatment, Care and Support

51. John was never aware of his infection, and I do not know of any difficulties James had in obtaining treatment for his illnesses or infections once diagnosed HIV positive. James writes in his Statement about receiving psychological support following his diagnosis, after having realised that he needed assistance and counselling **(WITN1082002)**. I believe that counselling was suggested at an early stage to him. He was seen by a Grace Bailey, the Principle Health Advisor at King's College Hospital who was very helpful to him. Following her departure, a Dr Gary Webb took over, who was less helpful. I know from James' Statement that a stress councillor was suggested, but he declined **(WITN1082002)**. He also saw Dr Robert Bore at The Royal Free who was helpful to him. This might have been a private consultation. Our family background wouldn't have been an obstacle to counselling. My mother and James also went to the London Lighthouse which my mother thought was lovely. As she recalls, ordinary hospices didn't want to know about people dying from AIDS.

52. **GRO-C**

GRO-C I do not think that the family as a whole was ever offered any psychological help.

53. To the best of my knowledge, my parents were never offered any support at all, from The Haemophilia Society, the government or anyone. In addition, with our family and friends focussed on supporting my mother, I think my father missed out on the support he needed, although I do not think he would have accepted psychological help if it had been offered.

54. I myself have sought counselling to help me with the issues raised by my brothers' deaths. I feel that many of my problems need external intervention in order for me to address them. I first began seeing a councillor after John's death, when I was living in Birmingham. I was waking up, going to work, coming home, waking up then going to work again. I found myself asking what it was all about, and so I sought help. I had a wobble about living in Birmingham, and had to talk to my mother about it. I felt like I needed her permission to move home. I eventually got a job in London and this felt more secure, although I still had difficult times.

55. I attended counselling after James passed away, but my attendance petered out. I began re-attending again after my father's diagnosis with dementia when he was in his 70s. I knew there was a pot of grief under there that that I needed help with. I needed counselling because there was no one else I could talk to about it.

56. I attended two separate periods of counselling. The first set of sessions I went to were £25 an hour, and I went for about six weeks in the 1990's. The period in the early 2000's was far more substantial and cost £40 an hour. I initially went weekly with sessions before becoming less frequent over the course of about four years. I have no idea how much I have spent on these sessions. My sister also paid for counselling.

Section 7: Financial Assistance

57. I do not have a great deal of information about any financial assistance that was provided to James. I know that the MacFarlane Trust provided James with some

money in order to fund a trip to Australia to see a friend. I do not know how he came to know about this funding, or what he had to do to obtain it.

58. My father assisted James in pursuing the Litigation in order to try and win some compensation. James himself wanted his solicitor to claim compensation in 1988. I think helping James with this was my father's way of coping, by trying to do something. James died just a few months before the Litigation was settled.

59. My father had attempted to obtain the amount given to couples in the settlement on behalf of James, to reflect the fact that he was with his girlfriend for the majority of his illness, he had commitments to her and because their relationship ended as a result of it (**WITN1082005**). He did not get this and instead was given the £23,500 pay out for a single person (**WITN1082006**). I still do not think the waiver that my father had to sign can possibly be legally binding. It felt like blackmail; sign or get nothing. My father was under immense pressure to sign this waiver, and considering the trauma we were all going through it is very surprising that he was subjected to this.

60. My father's correspondence with his solicitor shows that, once he was advised John's death may have been linked to HIV, my father also pursued financial support - successfully - related to John's condition (**WITN1082007 & WITN1082008**).

Section 8: Other Issues

61. In terms of my involvement with the Inquiry, it is good to share stories and to hear those of others. When you are going through these things it can feel like you are living in a bubble, and most people don't know what it is like and so hearing others' experiences is so helpful. It's a different world now, and AIDS is no longer a death sentence and it can feel like society has moved on from it. For me the scandal is always present, not just because of my brothers but because GRO-C GRO-C and so I am constantly reminded of the family history.

62. The angry part of me wants recognition for all the family loss, and for someone to show up at my door every day to say sorry for what happened. However, I imagine

that it is impossible to get compensation for unlived lives, but part of me believes that that should be forthcoming so that as a family we can try and create new memories, endow memorials or creative activities in honour of my brothers' memory. I don't know if there would be any merit to a prosecution now, but public recognition of the errors and oversights that led to this disaster need to be acknowledged by professionals, civil servants and successive governments.

63. I think here should also be a lasting national memorial to all those who were lost or affected by AIDS. A living memorial in the centre of London somewhere would be a fitting tribute with an annual service or celebration of remembrance each year for survivors and all those affected.

Statement of Truth

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

Signed ….. GRO-C

Dated……25. 9. 2019……