Witness Name: James Heatlie
Statement No.: WITN0832001
Exhibits: **WITN0832002 - 005**
Dated: 10/4/19

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JAMES HEATLIE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5 March 2019.

I, James Heatlie, will say as follows: -

Section 1. Introduction

1. My name is James Michael Heatlie. My date of birth is GRO-C 1950 and my address is known to the Inquiry. I am a retired Library Manager and I live with my Wife.

2. I intend to speak about my late son, Brian Heatlie and his infection with HIV which he contracted as a result of infected blood products used to treat his Haemophilia. In particular, the nature of his illness, how the illness affected him, the treatment received and the impact it had on him and our lives together.

3. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry to assist me with my statement. My Wife has also assisted me as a lot of time has passed since these events and I don't remember some of the dates and details.

Section 2. How Affected

4. Brian Heatlie is my late son and he was born on GRO-C 1977. He was diagnosed with severe Haemophilia A when he was just 1 years old; this came as a shock to both myself and my Wife, as there was no history of Haemophilia within the family.

5. Immediately after he was diagnosed, the nurses at the Haemophilia Centre at Manchester Children's Hospital started to give Brian the Cryoprecipitate. Brian had lots of bleeds when he was little especially into his joints, and getting teeth was a problem.

6. On one occasion, Brian had an allergic reaction to the Cryoprecipitate and so he was advised to change to Factor 8; he was 4 years old when he was put onto Factor 8. This product was fairly new in 1981 but I always assumed it was British Factor 8.

7. Even though I do not remember the exact date, I recall that Brian hadn't been on Factor 8 for very long before he was advised to change to imported Factor 8, which I understood came from the US.

8. The nurse at the Haemophilia Centre told my Wife and I that imported Factor 8 was "refined like fine wine not like British rough plonk". I went with what the doctors said and it was never suggested to me that Brian should be taken off the imported Factor 8.

9. Nobody ever told me that imported Factor was used as there was not enough British Factor available, though I was probably aware due to the publicity at the time. By this point however it was too late as Brian had already received imported Factor 8. Brian took Factor 8 as and when it was required; this was roughly once a week when he was younger.

10. Out of the blue, when Brian was 8 years old, I received a letter from Dr Evans (at that time Dr Evans was in charge of the Haemophilia Centre). The letter informed me that Brian had tested positive for HIV. It was a

tremendous shock. I feel that it wasn't right for them to communicate this type of information by letter; they should have done it face to face.

11. Shortly after we received the letter, my Wife and I were invited to a short meeting at the Haemophilia Centre with Dr Evans and Sister Shaw. During this meeting the doctor didn't give the impression that Brian would go on to develop AIDS but that it was just a possibility.

12. They told me that Brian would be monitored. I don't recall Dr Evans mentioning anything about Factor 8 but that doesn't mean to say he didn't. I wasn't provided with any information about the risk of passing the infection to others. Looking back, despite the fact that I was very upset during that meeting I think that only very general information was provided to us; I am sure that I would have remembered something if they had been more specific.

13. In hindsight I was not provided with enough information about HIV and AIDS and I got my information from other sources.

14. I didn't tell Brian about HIV. He used to go on adventure holidays with other Haemophiliacs, which were organised by the Haemophilia Society, and a few of them discussed HIV amongst themselves while they were on those trips. It was the same group of people each time except each time there were fewer and fewer of them; so Brian was aware of the seriousness of the situation.

15. After Brian had been diagnosed with HIV, he continued to take imported Factor 8. I don't remember if the doctor said anything to me about the link between Factor 8 and HIV but I remember that we never had any other choice.

16. When Brian was 8 or 9 he had a cerebral haemorrhage. He underwent a serious operation and I vaguely remember that he was given a blood transfusion.

Section 3. Other Infections

17. To the best of my knowledge I am not aware that Brian received any other infections as a result of being given infected blood products.

Section 4. Consent

18. The first time I found out that Brian had been tested for HIV was when I received the letter from Dr Evans saying that he tested positive.

19. I remember that I assumed Brian must have been tested for HIV at some point. Brian was a child at the time and so this test must have been done without mine or my Wife's consent.

20. I strongly believe that I should have been told immediately if there were any doubts over the safety of the blood products being used to treat Brian.

21. When the Imported Factor 8 came in to the Manchester Children's Hospital, Brian was one of the first to get it. It was reserved for Brian as it was in short supply. Looking back now I have started to question whether this was for the purposes of research.

22. I don't know whether Brian has ever been tested for Hepatitis C. If the doctors did the test, it was without our knowledge and consent.

Section 5. Impact

23. As briefly mentioned above, about 1 year after Brian was diagnosed with HIV he had a cerebral haemorrhage and I nearly lost him. He spent a number of months in hospital and was off school for almost 1 year.
24. It left him partially paralysed on his left side, his speech was affected initially and his personality changed a little bit but he got over it and he went back to school. From that moment on he suffered from a lot of bleeds, some of which meant he had to be in a wheelchair.

25. Brian attended Chapel St. Primary School. After this episode in hospital the school didn't want any responsibility for Brian. As my Wife reminded me, she had to collect him at lunch times. A Care Assistant at the school told me that some of the parents had expressed the view that they didn't want Brian to be mixing with their children. The Headteacher dealt with these problems and things calmed down, but I believe that the reason Brian was sent home on a lunch time was linked to this.

26. There was a lot of publicity around HIV at that time and there was an assumption that if you were a haemophiliac you were infected. The teachers did look after Brian but this was the start of the social problems at school and Brian struggled to make friends.

27. As my Wife has reminded me, at age 14 or 15, Manchester Children's Hospital suggested that Brian went under the care of Dr Mandal, who was an AIDS specialist at North Manchester General Hospital. So, I went with my Wife and Brian to meet Dr Mandal to have a discussion with him.

28. When Brian was 16 or 17, they put him onto AZT medication (for his HIV). I feel that this medication was started too late.

29. I remember that Brian was also vaccinated for Hepatitis B.

30. Whilst at Hazel Grove High School Brian started to develop infections like thrush in his mouth and Osteomyelitis, a fungal bone disease. The bone disease was really painful and he had to go into hospital to have a bone removed from his ear.

31. At one stage when Brian was in hospital, I went to see him. He was on a ward on his own. He said to me "I think I've really done it now Dad because there is no cure for this". That's when I knew that he really understood what HIV was and what was going on.

32. At age 15 Brian got shingles; this infection was again due to HIV. It was quite severe and he was on a drip in hospital. Around this time Brian was also due to sit his GCSE's and despite being unwell he managed to obtain

7 A's and 2 B's in his exams; he was very bright. Overall Brian suffered from two episodes of severe Shingles.

33. Because of his condition, Brian had to always stay close to a Haemophilia Centre and so if we went on holiday we would make sure that there was one close by. I wanted to take time off when Brian was well enough to go on holiday but people didn't understand that I couldn't book holidays in advance. I lived thinking "Is he going to be alright?" and "Can we go there?", but I didn't resent this.

34. Up until this point Brian had had a miserable time at school. He was bullied and he told me that he took his penknife to school for his protection. In the later stages of secondary school, Brian became increasingly anxious and lonely. He started to suffer from a lack of energy. From age 14 onwards Brian gradually felt increasingly ill.

35. When Brian was 16, he attended Aquinas Sixth Form College in Stockport. There was a completely different attitude at the College and things changed for Brian. He found really good mates and he would go to the pub with them to play snooker. They even came to visit him in hospital. It was such a transformation and he really enjoyed himself.

36. Brian remained with the Haemophilia Centre at Manchester Children's Hospital until he was transferred to the adult centre at Manchester Royal Infirmary when he turned 18. He was under the care of Dr Evans and then Dr Stevens.

37. Apart from what I now know about the Factor 8, I can say that I was happy with the care provided by the children's centre. The attitude changed at the adult centre.

38. Brian saw different doctors and they all excluded me. I felt it was unacceptable to put the expectation on a boy of that age. I really resented this at the time and I still feel bitter about this now.

39. The care was shocking. He was later sent to North Manchester General Hospital but things didn't improve. Whenever Brian had to attend hospital out of hours he was treated as though he was contagious until the haemophilia staff took over.

40. In his early teens Brian developed a keen interest in his medical treatments, and with the help of the British National Formulary (BNF), Brian would check the level of any proposed treatments and possible side effects.

41. Dr Stevens at Manchester Children's Hospital was always willing to discuss any issues with Brian. Brian also willingly participated in medical student training days supervised by Dr Stevens. In contrast, when Brian would question the proposed treatments, in order to reassure himself they were in line with the BNF, Dr Hay at Manchester Royal Infirmary seemed to get angry. This Doctor's attitude was clearly devastating for Brian's trust and morale.

42. Dr Mandal spoke to Brian about a drugs trial to cure HIV but unfortunately Brian didn't get onto it. I don't know why he wasn't given the trial. I tried to find out from Brian why they didn't accept him, but I didn't get anywhere. This was the only trial that was offered to Brian.

43. As he got older Brian became more independent and when he turned 17 he passed his driving test. He left Aquinas College with 4 A Levels and went to Salford University to study computers. Brian attended University for a term but he had to leave as he needed a break.

44. As his illness progressed, Brian suffered from more infections, loss of motivation, weight loss and loss of appetite requiring intervention to his diet in the form of supplements.

45. Brian went into Manchester Royal Infirmary in the closing stages of his illness. He seemed to be in there for a long time. He was on a ward with people with all kinds of ailments in a bed next to a severe alcoholic. The

beds were crammed in and I was lucky to get a seat when I went to visit. It was an awful place but there was nothing I could do; it tears me up thinking about it.

46. I went to see him on the Sunday, he was on the general ward but things were not looking good. I went back to visit him on the Monday. At this stage he was in a private room, an isolation room, and it became clear he wasn't going to last very long. I stayed with him until he passed away. Brian had developed C Difficile, a hospital infection and died on Wednesday, 20 March 1996.

47. I have never been told whether Brian had developed AIDS or not. On Brian's death certificate, neither HIV or AIDS are mentioned as a cause of death (I enclose exhibit **WITN0832002**). I was advised by Dr Bolton at the Manchester Royal Infirmary that the hospital wouldn't put HIV or AIDS on the death certificate as this would result in an inquest. At the time the coroner was calling in all HIV or AIDS related deaths. Dr Bolton suggested that we wouldn't want to have such a delay. I was in such a state at the time that I didn't question it.

48. I also remember that right at the end one of the nurses who was caring for Brian said that his body would be wrapped up and sealed in a plastic bag, so there would be no risk of contamination. What a dreadful picture.

49. Following Brian's death, I received a letter from Dr Hay at the Manchester Royal Infirmary. It suggests that either HIV or AIDS had killed Brian. (I enclose exhibits **WITN0832003** and **WITN0832004**).

50. The Haemophilia Society published Brian's death within their bulletin; the article stated that Brian had died as a result of HIV infection (I enclose exhibit **WITN0832005).**

51. Brian's Haemophilia was all consuming and I felt the need to protect him. It was exhausting at times with lots of hospital visits and when HIV kicked in, things started to get beyond my control and I couldn't do anything about it.

52. I didn't have a social life as I wanted to spend as much time as possible with Brian. Equally Brian didn't want to be too far away from his Mother and I.

53. Despite the fact that I didn't tell my parents about Brian's HIV as they were very elderly, the rest of my family knew about it and they have been very supportive and accepting. What we all went through brought us closer together as a family.

54. My Wife and I have stuck together as a couple but we still have difficulty in talking to each other about what happened to Brian because we fear upsetting each other even more. I can talk to other people about it such as family and selected friends or work colleagues.

55. When Brian was diagnosed, there was a lot of stigma around HIV; I was shocked at people's ignorance and intolerance.

56. The government publicity campaign seemed to make things even worse by emphasizing horrific outcomes. I have to say that I have never seen a change in people towards myself or Brian. If it ever cropped up, I wouldn't challenge it or want to argue about it. I felt it was best to only discuss the situation with close relatives or trusted friends. This aspect of constantly watching what I was saying, seemed like an unnecessary strain.

57. After Brian died I was off work for about 6 months as I had built up so much tension that I also suffered with depression. I lost my ability to laugh. To some extent I still have this and it still takes a lot to break through that barrier and laugh, but I accept that this is how it is. I get irritated when I see young people wasting their lives by doing stupid things.

Section 6. Treatment/Care/Support

58. Brian was referred to the Manchester HIV Persons Social Centre, a HIV support group that met in Manchester City Centre. He received therapies

and he was able to talk to others in the same situation. He drove himself there and back: he enjoyed it.

59. Brian also saw a counsellor at Manchester Royal infirmary but I don't feel as though it was beneficial to him.

60. I wasn't offered any counselling or psychological support whilst Brian was alive but I don't feel it would have helped as I don't like the formal attitude of a professional.

61. After Brian died we had a lot of friends who came and helped. A counsellor was suggested to me by Manchester Royal Infirmary but I didn't like her. I knew what was going on in my head, I didn't need someone to come and tell me that.

Section 7. Financial Assistance

62. My Wife and I were part of a legal case which resulted in Brian gaining access to the Macfarlane Trust. Brian received a lump sum of money which was placed into trust as he was under 18 at the time.

63. Brian later learned that he could apply for some money to be released at an earlier stage and so he wrote to the Macfarlane Trust. They released a small amount and he used the money to buy a computer.

64. When Brian died, we inherited the remaining sum left in the trust; it was £33,000.

Section 8. Other Issues

65. In 1990, my Wife and I joined a group legal action in which we were represented by lawyers Pannone Napier. I found out about this through the Haemophilia Society.

66. We met with Pannone Napier in their Manchester office and they dealt with the application to the Macfarlane Trust on our behalf. The solicitors were very nice and I had no problems with them.

67. This legal action resulted in a lump sum payment from the Macfarlane Trust being placed into trust for Brian. This was on the condition that the government were not accepting liability for what had happened to Brian and that he wouldn't get any more money if something cropped up again. I think this was the first thing Margaret Thatcher did when she took over. She set up the trust fund to tie it all up so it could be forgotten about.

68. Pannone Napier also obtained all of Brian's medical records which were passed to me. I had a massive file of original records but these were thrown away when I moved house.

69. I have been asked whether I have any expectations from the Inquiry, I want to know who decided that the blood products were going to be alright to use. I want to find out if anybody knew that the products weren't alright to use but wouldn't admit to it. I want the truth to come out. I want the Inquiry to bring light on who was making all the decisions. I don't care what happens to them but I want to know who they are.

Statement of Truth

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

Signed GRO-C

Dated 10/4/19