Witness Name: Lynda Heatlie
Statement No.: WITN0833001
Exhibits: **WITN0833002 – 005**
Dated: 10th April 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF LYNDA HEATLIE

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

I, Lynda Heatlie, will say as follows: -

Section 1. Introduction

1. My name is Lynda Heatlie. My date of birth is GRO-C 1946 and my address is known to the Inquiry. I am a retired Library Assistant and I live with my Husband.

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 Husband 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.

5. This came as a shock to me as there was no history of Haemophilia within the family. I have since learnt that I am a carrier for the disorder. After Brian was born, I stopped working as I felt that because of his Haemophilia I couldn't leave him with others.

6. Once he was diagnosed, the nurses at the Haemophilia Centre at Manchester Children's Hospital immediately started to give him Cryoprecipitate. He had lots of bleeds when he was little, getting teeth was a problem and he suffered from bleeds into his joints.

7. On one occasion, Brian had an allergic reaction to the Cryoprecipitate and so he was advised to change and to start taking Factor 8: he was 4 years old. At this age his veins were more developed meaning I was able to administer his injections at home. This product was fairly new in 1981 but I always assumed it was British Factor 8.

8. 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. I don't remember the exact date. The nurse at the Haemophilia Centre told my Husband 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. I was never told that imported Factor was used as not enough British Factor was available. What I know is that the Haemophilia Centre used to put aside the imported Factor 8 for Brian.

9. When Brian was 8 years old I received a letter from Dr Evans, who at the time was in charge of the Haemophilia Centre. The letter was totally out of the blue and it informed me that Brian had tested positive for HIV. It was a tremendous shock. I feel that this information should not have been

communicated by letter and that at least, they should have done it face to face.

10. Shortly afterwards my Husband and I were invited to a brief meeting with Dr Evans and Sister Shaw at the Haemophilia Centre. He explained that Brian may go on to develop AIDS but that he also might not. I was told that Brian would be monitored. Dr Evans said that 8 people out of those tested had been infected. I believe around 15 individuals had been tested but I am not sure about it. I don't recall him mentioning anything about Factor 8 (whether the infection came from the first Factor 8 or from the American or whether Cryoprecipitate had anything to do with the HIV infection) but that doesn't mean to say he didn't. Very little information was provided at this meeting about Brian's HIV infection.

11. In hindsight I was not provided with enough information regarding HIV and AIDS too. I was the person giving Factor 8 injections to Brian but I don't remember receiving any advice about the risk of being infected or to infect anybody else with HIV.

12. I don't remember telling Brian that he had HIV, at the end of the day he was only 8 years old. 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.

13. After Brian's HIV diagnosis, he continued to take imported Factor 8. A bleed couldn't not be treated and so Brian needed to take some Factor 8 all the time. I just went along with the experts and I don't remember any other choice being given to me.

14. 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.

15. I also vaguely remember being told by the Haemophilia Centre that Brian probably was infected with Hepatitis C but that was years and years later.

Section 3. Other Infections

16. I am not aware that Brian received any other infections, other than HIV, as a result of being given infected blood products.

Section 4. Consent

17. Due to his Haemophilia, Brian's blood was tested regularly but as I understood it, this was to test to see if he developed antibodies. The first I knew about any HIV testing was after I received the letter from Dr Evans regarding Brian's HIV diagnosis and I assumed Brian had been tested for HIV at some point. So, I am pretty sure that he has been tested but I didn't know about it.

18. Brian was a child at the time and so my Husband and I had to give our consent to any test or treatment; we never consented to the test so this must have been done without any consent at all.

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

Section 5. Impact

20. 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 he had to be off school for almost one year. The haemorrhage left him partially paralysed on his left side, his speech was initially affected and his personality changed a little bit, but despite all these things he got over it and 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.

21. Brian attended Chapel St. Primary School. After this episode the school didn't want any responsibility for Brian. I had to collect him at lunch times and they wouldn't let him go out with the other children at break times. This

meant that Brian couldn't make friends and caused some social problems as he was obviously different. I never told the school he had HIV.

22. At age 14 or 15, Manchester Children's Hospital suggested that Brian should be under the care of Dr Mandal, who was an AIDS specialist at North Manchester General Hospital. I went with my Husband and Brian for a discussion with Dr Mandal. At age 16 or 17, Brian was put onto AZT medication for his HIV. I feel this medication was left too late. In that period, he was also vaccinated for Hepatitis B.

23. Whilst at Hazel Grove High School, Brian started to have 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. He also had it in his arm but nothing was done about that and they didn't tell me about his arm until just before he died.

24. At age 15 Brian got Shingles. This was an opportune infection due to his HIV. It was quite severe and he was on a drip in hospital. I remember asking Sister Shaw if this was the beginning of the end but she assured me it wasn't. Brian was due to sit his GCSE's around this time and despite being unwell he managed to obtain 7 A's and 2 B's in his exams; he was very bright. In all Brian suffered from two episodes of severe Shingles.

25. 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 he gradually felt increasingly ill.

26. When Brian was 16, he attended Aquinas Sixth Form College in Stockport. The college were aware of Brian's HIV infection and they had Sister Shaw from Manchester Children's Hospital come to give a talk to the staff about HIV. It was a very caring college.

27. 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. I was happy with the care that the children's centre provided

although, if I think about what I now know about the Factor 8, I am not sure I still have the same opinion.

28. The adult centre completely excluded me. The doctors would literally draw the curtain around Brian and left me out. The care was inadequate and he was later sent to North Manchester General Hospital; but things did not improve. Whenever Brian had to attend hospital out of hours he was treated as though he was contagious until the haemophilia staff took over. It was horrible.

29. 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.

30. 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.

31. Dr Mandal spoke to Brian about a drugs trial relating to HIV but unfortunately Brian didn't get on it. This was between Brian and Dr Mandal and so I don't know all the details. I learnt that others who had been on the trial lived on and maybe still are.

32. As Brian got older, he became more independent and at 17 he passed his driving test. He left Aquinas College with 4 A Levels and went to Salford University to study computers.

33. He attended University for a term but had to leave as he needed a break. At this point he had lost a lot of weight and had very little energy. 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.

34. In 1995, Brian went into Manchester Royal Infirmary then came home for a short time for Christmas and then went back into hospital. I was told there was nothing they could do. He suffered from awful diarrhoea and couldn't eat anything. Dr Bolton put him on morphine to help him with the pain but he developed C Difficile, a hospital infection.

35. Brian died on 20 March 1996.

36. I was never told whether Brian had developed AIDS or not. Neither HIV or AIDS are mentioned as a cause of death on Brian's death certificate (I enclose exhibit **WITN0833002**). 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 the delay of this. At that time, I was in such a state that I didn't even question or think about it.

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

38. 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 **WITN0833005).**

39. Following Brian's death, I received a letter from Dr Hay. It suggests that Brian died peacefully but he didn't die peacefully to my mind (I enclose exhibits **WITN0833003** and **WITN0833004**).

40. I don't know any other haemophiliacs at the hospitals in Manchester who were infected with HIV. I do know one lady who had a daughter with Von Willebrand's and they are now part of the inquiry.

41. What I went through with Brian was very stressful. I devoted all my time and attention to him; it took over my life. I would have gone back to work, as I enjoyed it, but Brian was more important. It was exhausting at times with lots of hospital visits.

42. I suffered with headaches and high blood pressure. I didn't have a social life as I wanted to spend as much time with Brian as possible. Equally Brian didn't want to be too far away from his Father and I. Whilst Brian was growing up, my main worry was Haemophilia but later the impact of HIV took over. I would say that the worst part was the unknown.

43. There was a lot of stigma towards HIV at the time Brian was diagnosed. I was shocked at people's ignorance and intolerance. The government publicity campaign seemed to make things worse by emphasizing horrific outcomes. I didn't see a change in people towards myself or Brian. I felt it was best to only discuss the situation with close relatives or trusted friends. This aspect, constantly watching what I said, seemed like an unnecessary strain.

44. After Brian died I was depressed and mentally it was horrible. My whole life had been Brian and his death left a big hole. I didn't have a lot of close friends, so I didn't discuss it with anybody. What we all went through brought us closer together as a family. My Husband and I have stuck together as a couple but we have difficulty talking to each other about what happened to Brian through fear of upsetting each other even more. Eventually I did go back to work as a Library Assistant.

Section 6. Treatment/Care/Support

45. Brian was referred to the Manchester HIV Persons Social Centre, a HIV support group that met in Manchester City Centre. He received therapies and was able to talk to others in the same situation. They offered things like head massages and the people there looked after him very well.

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

47. I wasn't offered any therapy or psychological support whilst Brian was alive but I wouldn't have wanted professional help. 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.

Section 7. Financial Assistance

48. My Husband 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.

49. Brian later learned that he could apply for some money to be released early and so he wrote to the Macfarlane Trust. They released a small amount and he used the money to buy a computer.

50. When Brian died, we inherited the remaining £33,000 which had been put into trust for Brian by the Macfarlane Trust.

Section 8. Other Issues

51. In 1990, my Husband and I formed part of a joint legal action in which we were represented by lawyers Pannone Napier. I found out about this through the Haemophilia Society.

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

53. This legal action resulted in a lump sum payment from the Macfarlane Trust being placed into trust for Brian. As my husband reminded me, we received

this payment on the condition that we couldn't come back and ask for more money.

54. Apart from that, we have never been part of any campaigning or group litigation.

55. I have been asked if I have any expectation from the Inquiry; I want to know the truth about what happened. I'm not in it for the money. Nothing will bring Brian back. But I want to know what happened to him, if the first Factor 8 he received was infected or if the American one was (or both). I want to know if someone knew about the fact that infected blood products were given to people like us.

56. I want to have answers to all the questions that in these years have remained silent and unanswered. I want to know if the doctors knew about it.

Statement of Truth

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

Signed GRO-C

Dated 10th April 2019