Witness Name: Marcus Richard Lewis Statement No: WITN2955001 Exhibits: WITN2955002 Dated: March 2019

### INFECTED BLOOD INQUIRY

## FIRST WRITTEN STATEMENT OF MARCUS RICHARD LEWIS

I, Marcus Richard Lewis, will say as follows:-

### Section 1. Introduction

- 1. My name is Marcus Richard Lewis. I was born on GRO-C 1974 and I live at GRO-C GRO-C
- 2. I am a paramedic. I joined the service when I was 20 years old. I have two children.
- 3. I make this statement on behalf of my late twin brother, Damian Farley Lewis. He was born on **GRO-C** 1974 and died on **GRO-C** 1995 aged 21 from AIDS.
- 4. My mother, Joan Lewis, has also produced a witness statement, 'WITN2768001' for the Inquiry.
- 5. This witness statement has been prepared without the benefit of access to my late brother's full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

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### Section 2. How Affected

- 6. Damian had medical problems since he was 3 years old. He started having seizures at age 3, caused by a subarachnoid cyst which was diagnosed later in childhood. He was misdiagnosed with epilepsy for which he started Tegretol medication which in large doses causes side effects such as bone marrow failure.
- 7. I recall Damian became very sick around 1983, he went to Morriston Hospital (MH) first and then to the Hammersmith Hospital (HH) in London. He needed a Bone Marrow Transplant (BMT) from me. I refused as I was scared of needles. I was then taken to Hammersmith Hospital (HH) where a doctor sat me down and told me that my brother would not survive if they did not do the procedure on him. I recall asking my mother for a skateboard in exchange for donating my bone marrow.
- 8. The bone marrow transplant was successful and Damian was doing well after the procedure. I was told that he had blood transfusions prior to the procedure and after the procedure. A record of the batches that he was given is exhibited at 'WITN2955002'.
- 9. I recall when I was about 13/14 years old, my father and mother took me aside and told me that Damian was not well and he had an infection. I thought he had a normal infection, which he would be medicated for and that he would get better. I did not know at the time that he had HIV.
- 10. For further information about how my brother was infected, please refer to my mother's witness statement.

## Section 3. Other Infections

11.1 wish to rely on my mother's witness statement in relation to this section.

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#### Section 4. Consent

12.1 wish to rely on my mother's witness statement in relation to this section.

#### Section 5. Impact of the Infection

- 13.1 know Damian suffered Mental and Physical effects as a result of the HIV infection, I noticed that he had Boils on his Scalp, and bottom. He also had psoriasis, which was all over his body. He also suffered from frequent infections, Diarrhoea, thrush, pruritus, and malaise. He also suffered from hair and weight loss. I also noticed that he was very careful around people. I recall his mood changing, but thought that was all part of growing up. I thought something was wrong when he was careful when I would go near him. He would not touch me and was careful not to leave any saliva or blood anywhere. He lost a lot of his hair. I now believe that the above symptoms were as a result of the HIV.
- 14. Damian did not really have a social life. He was very withdrawn and kept himself to himself. He did not talk to me about the infection.
- 15.1 sacrificed my social life for Damian. My friends used to go on holidays but I never went, as I felt guilty leaving him behind and enjoying myself. I was either at school, or at home with him or working. I had to grow up pretty quickly at the time. From an early age, I was never a typical teenager. I was very responsible. I used to do general household chores such as gardening and shopping. I was also working at the same time. I was a bit of a miser then and I used to save up the lunch money that I got for my school dinners to buy something that could be used in the house, for example, gardening equipment. We were very close as brothers and used to do everything together.
- 16. Damian and I used to spend a lot of time in the study. He liked to read a lot of books and comic books, play and watch TV. At age 20, 1 recall I was with Damian in the Study one day and he was reading his comic book and then he started to stare into space as wad unable to speak properly, and dribbling.

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called my mother who called the doctor and he was admitted to Singleton Hospital (SH), Swansea. After a few weeks, he was transferred to Morriston Hospital (MH), Swansea and started to deteriorate rapidly. He was moved to an ICU and put on a ventilator and later died of AIDS.

- 17. Although it was Heart breaking at that point to know what my brother was going through, it was not until after his death I started to feel guilty after I saw him on a ventilator in ICU. Whilst he was in ICU I only went to see him once as I could not bear to see him in that state, I found the sight of him to traumatising. I have never forgiven myself for that. After Damian's death, I started to go out and get into a lot of fights. I was very angry and bitter towards people and little things that people did annoyed me. I do not like people who bully or talk down to other people. I always tried to look after people, and would go an extra mile to help people, even at work. It was very out of character for me to be angry and bitter.
- 18. There was definitely a stigma attached to the HIV at the time. As a result, my parents kept Damian's infected status very private. The media portrayed HIV as a 'gay disease' and my parents were worried about how Damian would be treated if anyone found out.
- 19. After his death, it devastated us as a family. People were trying to console us. My mother was taken to pubs and she started drinking heavy and became an alcoholic lasting for 11 years. She was completely devastated by his death, could not cope with losing him and could no longer function. Her life from then onwards went downhill.

20.	My father also turned to alcohol after Damian's death.	GRO-C
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	GRO-C	My mother gave up
1	drinking 2 years after my father died. I can only wond	er if Damian hadn't been

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infected with contaminated blood where would we be today, and how different our lives would have turned out. I feel completely heartbroken when I think back to all the suffering he went through. I also admire how brave he was. This was a difficult time for me. I had just lost my brother and later found out that he had HIV and then my parents turned to alcohol. I had to take care of my parents and the household and be a responsible person at a young age. It was hard and my life was tough when Damian died.

- 21. My grandparents were also affected by Damian's death. It was a very difficult time for everybody.
- 22. I suffered work-related effects as a result of Damian's death. I had an emotional breakdown at work and to make it worse, my manager was being difficult and started wearing me down knowing that my brother had died. I snapped at that point and threatened the manager. I then walked out of there and never went back. I did not stay long enough to know if I was sacked or not. Again this was very out of character for me.

# Section 6. Treatment/care/support

- 23.1 do not know if my brother faced any difficulties or obstacles in obtaining treatment, care and support. He was at the age where he was dealing with his own medical care.
- 24.1 do not believe Damian was offered any counselling or psychological support. I was not offered any counselling. I believe that my parents and I should have been offered counselling, especially when my parents turned to alcohol after Damian's death.
- 25. Personally, I believe more should have been done for my mother but instead she was left to deal with the whole situation herself.

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#### Section 7. Financial Assistance

26.1 wish to rely on my mother's witness statement in relation to part of this section.

#### Section 8. Other Issues

- 27.1 was devastated that I did not know Damian had HIV until after his death. However, I believe it was Damian's wish that I was not told about it. It was not until the Inquiry hearings that started and going through his medical notes that I feel furious and heart broken about what happened to him. I cannot describe how I feel right now. Damian being infected has ruined our family, our lives.
- 28. What has annoyed me the most is when I was reading through his medical letters, I noted that the doctors knew Damian had HIV before my parents were informed about it. If the hospitals knew that the batches of whole blood were infected, they should have stopped using them. If a batch of food in a supermarket was bad they would get rid of it all as there is a possible risk, so why did the hospitals continue to give bad batches of blood to my brother.
- 29. They infected a little boy with HIV which I think was a total disregard to life. No amount of money could repair the years of heartache that we have all suffered as a result of the Contaminated Blood Scandal. We had to deal with a sick father with cancer who had lost his son. My mother should have been there for him but instead she turned into an alcoholic. We could have done more for my father but could not as we were all heartbroken by Damian's death. My father should have enjoyed the last few years of his life but he was just sitting home. It was not easy. The last few months of my father's life were dreadful, and again heart breaking when I look back at how he suffered.
- 30. I want people to understand how hard it has been for my family. I found watching the commemoration very hard. That really upset me seeing the photos of all the people who had died as a result of being given infected blood products.

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