Witness Name: Jill Cunnington
Statement No.: WITN0154001
Dated: 10-4-19.

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JILL CUNNINGTON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 8 February 2019.

I, Jill Cunnington, will say as follows: -

Section 1. Introduction

1. My name is Jill Cunnington. My date of birth is GRO-C 1960 and my address is known to the Inquiry. I am 59 years old with 3 sons and 6 beautiful grandchildren. I work part time at my local supermarket. I intend to speak about my HIV infection and that of my late husband, Robert Cunnington. In particular, the nature of our illness, how the illness affected us, the treatment received and the impact it had on our family and our lives together.

2. I confirm that I do not have legal representation.

Section 2. How Infected

3. My late husband, Robert Cunnington was born on GRO-C 1958. He was born with severe haemophilia A. He was treated with cryoprecipitate and, later, he was switched to Factor VIII treatment. Robert required regular treatment with Factor VIII and also with painkillers, but received no other treatment and no blood transfusions. He was under the care of the Queen Elizabeth Hospital in Birmingham. We were later told during a subsequent HIV litigation case that the blood products Robert had received had come from America and that it had not been screened or cleaned.

4. In 1985, Robert went to hospital for a vasectomy (the hospital has subsequently closed and I do not recall the name). During a routine blood test he was told there was something wrong with his blood and they referred him to the Haemophilia Clinic at the Queen Elizabeth Hospital. Both Robert and myself were called in for testing.

5. It took six weeks for the results to come back; the wait and the uncertainty were horrible. Robert's test came back HIV positive. He was taken in to Dr Franklin's office and told he had HIV and had a maximum lifespan of 10 years. Our eldest was only 5 years old and our twins were only 3 years old. Robert was very upset about what would happen to our young family. He was not given much information at all about the disease, though I do not think much was known at that time. He was not given any advice on precautions to take and there was no warning about the possibility of passing the virus onto me through our sex life.

6. Initially, my blood sample was lost so I had to have another test done. I was advised I was not infected and would most likely be okay. However, six weeks later I was also told in Dr Franklin's office that I was HIV positive and that it was a death sentence. I feel the way in which we were told could have been more sensitive and caring.

7. We were given minimal information about the illness and were offered very little support. We found out a lot of information about HIV from the television and magazines and our own research. There was a health nurse at the haemophilia clinic (I do not recall her name), but she was about as useful as a box of chocolates. Her main concern was getting our sex life back on track, but who really can think of that when they have been given a death sentence.

8. Our children were all tested and, fortunately, were not infected. I was 25 when I was infected and I am now 59 so I consider myself to be doing well to have lived more than 30 years with HIV and the virus remains well controlled as long as I take my medication.

Section 3. Other Infections

9. As far as I am aware, I am only infected with HIV. I have been tested for Hepatitis C and given an injection to hopefully prevent it. I do not know whether my late husband had Hepatitis C as well as HIV because he died only four years after becoming infected.

Section 4. Consent

10. I believe we were both always treated with consent and as much knowledge as anyone could have provided at that time, though this was not much. As far as I know, we were not tested or treated as part of any research.

Section 5. Impact

11. Robert lived the last four years of his life with this infection and died aged only 31. With the haemophilia, Robert had already been in and

out of hospital all his life, so he could have really done without the HIV infection.

12. When Robert was told of his infection, he was very worried for our family, particularly our children. I always remember his comment that it was "a ticking timebomb". He knew there wasn't much hope. Robert became progressively more ill and any other malady or infection would be a very real concern. Robert gave up socially and would sit on the settee and just stare blankly; he pushed all of us away. This was difficult to deal with for myself and for the children.

13. About 6 months after the diagnosis, Robert started treatment on AZT. This treatment would knock him about. He would have to wake several times a night to take the drugs, but the drugs just made him more ill. He had to stop treatment, though had other trial cocktails of drugs until his death. Robert would suffer from diarrhoea, nausea, balance issues and weakness. I remember once the diarrhoea was so bad that we had to go to hospital and Robert actually messed himself whilst there. No one cleaned him up so I did it myself. Robert was 11 stone when he was infected but only 5 stone when he died. He was like a skeleton; he could not move or walk so I would have to carry him everywhere and he was forced to use a wheelchair.

14. Robert died on a Thursday. I recall it so vividly. I had been up with him all night. He used to sleep on the settee and I would sleep downstairs with him. He had been struggling to breathe. I called his mother and father and they came immediately. He had a chest infection that had developed into pneumonia. He was very ill and it was a slow and painful and horrible death. He was all grey. I asked if he was alright and he said he didn't feel okay. I tried to give him oxygen but he wouldn't have it. If you looked into his eyes they were blank, as if he wasn't there. He began flailing his arms and I held him in my arms, trying to prevent him from hurting himself. He looked up

at me and I said to him just go. And he died. No one should have to die like that.

15. I called the hospital to tell them he had passed away and they did not care. I called our GP who had always been excellent and he came out and stayed until the undertakers came. He supported us with the coroner's court (Doctors from the Queen Elizabeth Hospital were asked to come along but none showed up). My GP now is the same, very supportive and caring. The cause of death was listed as HIV AIDS and pneumonia.

16. We could not have the funeral until 6 weeks later because we had to wait for the coroner. At the funeral we had a viewing and it was horrific because he was so sick when he died.

17. After his funeral, press came around asking questions and even some of our neighbours, wanting to know what had killed him, but I just ignored them.

18. Caring for Robert took its toll on me. It was horrific holding the man I loved in my arms as he died and I will never forget it. When I am alone and quiet I remember that moment; it stays with you and you relive it every day.

19. I get very tired and when Robert got sick I took everything on my shoulders trying to be the mum and dad to our children and care for Robert. I was scared to pass on the infection to others and I have never had another relationship.

20. I did not start treatment until after Robert had passed away. I did have significant side effects, including diarrhoea, sickness and at one stage my skin went yellow. I had pancreatitis and was rushed to hospital with suspected gallbladder issues. I do not remember the names of the drugs I was treated with now, but some of the tablets were huge. I

was initially on 16 tablets a day but now I only need 4 tablets a day. I seem to be fine as long as I take my medications so I hope they are doing their job.

21. There were no other treatments that I thought I should have been given as far as I am aware. However, my infection did affect my other medical treatment. In 1986/1987, just after I was diagnosed, I had a lump removed from my hand. This was supposed to take place at the Queen Elizabeth Hospital. They initially postponed my treatment three times. My doctor was told that they postponed the procedure because of my infected status, though they never told me this. On the fourth attempt, they did proceed, but I was put in a side room in isolation. A sign was placed on the door saying "infected person" and anyone who came in wore gloves and gowns. This was very hurtful.

22. Even now, I am always last to be treated, such as for each of my knee replacements and my hysterectomy. My dentist is very good, but will not treat anything major or remove any teeth so if I ever require this treatment I will need to attend a dental hospital. I have been bounced around from hospital to hospital quite a bit, but overall the care was and is good.

23. Socially, the impact has lessened over the years. When I was first diagnosed, there was more stigma. I told a few friends who knew Robert and myself very well and they were distant at first, but they came around. I have not lost friends because of my infection, but I have not told everyone about the infection. Colleagues at work, particularly those of older generations, can be judgmental about it when it is mentioned on the news. It's a strange irony though, they don't know I am sat there amongst them and infected.

24. The stigma has lessened over the years and impacted Robert more than it impacted me, as it was not right in those days what people said about HIV. Robert told his manager about his diagnosis and his

colleague at work made his life miserable, until Robert quit. I understood the risk of Robert being a haemophiliac and HIV infected was dangerous, but it was still unfair the way he was treated.

25. When Robert died, some local children found out and would taunt my boys that their dad died of AIDS, which wasn't nice for them but they just ignored it.

26. In 1996, my car windows were all smashed and some of the house windows were broken, too. I am not positive this was due to HIV stigma, but I did suspect it might be. I did think of moving to avoid the stigma, but thought to myself I should not have to move away from my home and my memories due to ignorance.

27. The infection impacted both Robert's work and mine. As I've mentioned, Robert was eventually forced to quit his job because of the stigma and hostility of his manager and work colleagues. Due to his poor health, Robert was never able to work again. Before his infection, Robert had lived a normal life and had always worked.

28. I suffered contantly from fatigue so I made the decision to drop down to part time work, which was far more manageable. I still work part time four days a week.

29. Financially, we suffered quite badly when Robert had to quit work and whilst I was caring for him. We lived hand to mouth for a while. I took a job cleaning other people's homes just to make ends meet.

30. Now, I need to declare my HIV status for travel insurance. If you shop around, it is not too expensive, but you need to know if anything happens you will be covered. It is difficult taking medications and letters with you to explain everything, though.

31. I do not have life insurance, as I am sure no one would touch me. I have received the cold calls selling life insurance, but as soon as I mention HIV they hang up.

32. Fortunately, the impact on the children has been minimised because I was determined they would still have a childhood. It was still very hard to explain to them that someone they loved would not be around for long. Our lives were on hold for a while, but we have got through it together. I remember when Robert died my eldest who was only 9 said to me he would be man of the house now, but I made sure they were happy. They did ask about their father as they grew up and the grandkids now ask if granddad would have liked them. I am lucky to have had a very supportive family. I know my sons are all there whenever I need them and I have three wonderful daughters-in-law and my 6 wonderful grandchildren. There are no secrets between us and my grandkids especially keep me going now, mentally and physically.

33. It is incredibly sad that Robert never got to see his kids grow up and that they cannot really remember him. It is sad that Robert never got to meet his grandchildren, as he would have loved them. Ultimately, it was a life not lived, a life tragically lost, but also all our lives were put on hold and the pain of missing Robert never goes.

Section 6. Treatment/Care/Support

34. Neither Robert nor myself were offered any psychological support. This is despite being effectively handed death sentences at the time of being diagnosed. Even when Robert passed away nothing was offered. We had no help moving forward after the infection was diagnosed. I have now got so used to being infected, having been infected for so long, that I just get on with it.

Section 7. Financial Assistance

35. We were never made aware of the financial assistance formally. However, one of Robert's friends who also had haemophilia and was infected with HIV told us about the Macfarlane Trust. Robert never got to see the money. I received an ex gratia payment of £25,000 for Robert about 12 months after he died, but I never received one. I also got money from the HIV legal actions, which paid off the mortgage so at least that was one less bill to worry about. Approximately £5,000 for each of the boys was taken away from the payout and put into a Queen's Trust for them when they turned 18, which was good as it got more interest.

36. I remember there being some paperwork to sign on to the Macfarlane Trust, but that it was quite easy. As far as I recall, there were no obstacles or preconditions and I don't remember signing any undertaking. I was offered a loan from the Macfarlane Trust if I needed it to buy items around the house, but I always used my own money instead and refused the loan.

37. Now, the Macfarlane Trust is EIBSS and I receive around £2,000 a month, which is more than the Macfarlane Trust ever gave me. Whilst the money keeps me going, I would much rather have Robert back and I would give it all away to have him back.

Section 8. Other Issues

38. No one should have received infected blood or had to live as Robert did before he died. No one should have died such a horrible death from an infection given to them by the treatment that was supposed to help them. No one should have the memory of holding their loved one as they died. Robert's life was wasted as were many others.

39. People want to know why Robert and people like him had to die for something they needed to live. We should be able to receive life saving treatment and trust that it is safe. I am angry, and a lot of people are angry, that this treatment was a death sentence. In our day, everyone was busy blaming the homeless, the Americans and the gays, but the blood should have been screened and it should have been cleaned. People need to know the truth about what happened and how it happened and it should no longer be swept under the carpet.

Statement of Truth

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

Signed **GRO-C**

Dated 10-4-19.