

Witness Name: Susan Lee  
Statement No: WITN5271001  
Exhibits: 0  
Dated: January 2021

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF SUSAN LEE

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I, Susan Lee, will say as follows:-

#### **Section 1. Introduction**

1. My full name is Susan Harriet Lee. I was born on GRO-C 1951 and I live at GRO-C
2. My husband, Derek Hope Lee (born on GRO-C 1933), was co infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) through contaminated blood products. He died on 13th April 1988, aged 54.
3. This Statement has been prepared without the benefit of access to Derek's medical records.

#### **Section 2. How Affected**

4. Derek had severe Haemophilia A. He was treated at the Manchester Royal Infirmary (MRI).
5. Derek and I shared a social circle of mutual friends. We all knew that he had haemophilia. He had damage to his joints through the bleeds and arthritis. He drove an adapted car and walked with a stick. Other than that, he was fine/relatively fit. He was an Educational Psychologist working full-time. We fell in love and we married on 18<sup>th</sup> April 1984. It was a second marriage for both of us and we had four children between us, two each.
6. I went to Derek's haematology appointments with him. I knew that Derek had been infected with hepatitis and I knew of the potential for the infection to irreversibly damage his liver and spleen. I also knew that that a secondary viral infection could destroy Derek's spleen and his antibodies could only then be produced in his bone marrow.
7. Derek was an intelligent and articulate man. He was a Principal Educational Psychologist and he knew that hepatitis was a serious health concern, but he pretty much got on with it. He kept his FVIII concentrate at home to use when he had a bleed and so that he didn't have to go to hospital for treatment. Derek was a severe haemophiliac and needed that treatment. He was glad to have it. He remembered in his childhood being treated with snake bite and with fresh blood from his father transfused into the back of his knee.
8. After Derek found out that he was HIV positive it was horrendous. We were so distressed. We had not been pre-warned of the risk of HIV beforehand. I do not now remember how, when and where Derek was notified of it. I have blocked the memory of a lot of that time as a coping mechanism. I do know that he was one of the first to be infected and one of the first to die from AIDS and I do remember (very clearly) the fallout from the diagnosis.

9. We were given very little information to help us to understand and manage the infection. Derek did latterly have some AZT treatment, but that was it. In caring for Derek until he died, I was constantly exposed to the risk of cross infection.

### **Section 3. Other Infections**

10. Derek did not have other infections. I remember that I was offered, and had a jab for the Hepatitis B Virus by the Haemophilia Centre.

### **Section 4. Consent**

11. I do not think that Derek was tested or treated without his consent. As stated, he accepted that he needed treatment and I do not think there was any viable alternative for him.
12. I am clear in my mind that the fault for the treatment of haemophiliacs with contaminated blood products lies squarely with the Government. Our Government imported blood from the USA sourced from the prison population and others selling their blood for money. The intended facility in Elstree that was going to provide clean home sourced blood products was never built because of cost.

### **Section 5. Impact of the Infection**

13. No words can properly describe our distress at learning that Derek had HIV. As stated, I have blocked out a lot of the finer details. I do not remember dates as I have tried to bury a lot of it. I find it distressing to relay what I do remember now, over 30 years later. It was a horrendous time. Derek developed Kaposi's Sarcoma through his AIDS infection. Some medical examiners even came to see him to use his lesions for medical illustration.

He went to a conference as a medical volunteer and I remember him taking his top off revealing the unsightly contagious lesions to the attendees.

14. Intimacy was out of the question. We were both terrified that I would become infected and that Derek would effectively kill me. Prior to this, we each had a normal life expectancy to enjoy. We became celibate.
15. Derek had had a knee replacement which was rare for a haemophiliac. He was left with a wide open, gaping wound that never healed. I had to dress it constantly.
16. On one occasion the blood from Derek's wound splattered my face and covered my hands with his blood. I had cracked fingers and I had to pour neat bleach all over my hands to clean them. I didn't know what else I could have done.
17. I was told to always put the used dressings into a yellow biohazard waste bag and leave them outside (in full view of our neighbours) for the bin men to dispose of separately and correctly. I watched and saw that didn't happen and that the bag got thrown in the back of the bin lorry instead. I rang the Haemophilia Centre and was then told I should burn the dressings. The dressings were too big for me to manage to burn on my own. My only solution was to fight through a broken fence behind the house to sneak the bags through and leave them to be incinerated with the waste from the hospital safely and securely.
18. Derek had a couple of bouts of pneumonia and needed hospitalising. He was taken to hospital on one occasion by paramedics in hazmat suits. Some of our neighbours came out to look. I had to try to explain what was happening to my children.
19. Despite Derek being confined to a wheelchair and between his bouts of pneumonia, he continued to work for as long as he could (I would lift him in

and out of his car and I cannot now recall how he managed at the other end). He took early retirement a couple of months before he died. We were not struggling financially. Derek's pension and lump sum were needed by us to get by, but I also worked full time.

20. We were lucky enough to have some wonderful and very supportive friends throughout. They wouldn't come to my house and wouldn't go to the hospital with me. They would say 'Oh, I don't like hospital visiting' but I never had to keep anything hidden from them. The District Nurses were very good too. I taught blind and partially sighted children on a peripatetic basis. The school had to consider the risk of infection to the children and staff because it was not unheard of for the children with issues to bite and scratch. I was taken under the wing and very much protected from a lot of negative comment by an older gay colleague I was very close to and knew about Derek. He always found a plausible excuse for me to not be in the room or at meetings when issues a little too close to home for me were discussed.

21. Derek was admitted to Huddersfield Hospital for a planned leg amputation. We were told that he would ultimately die without an amputation, but he had just a 50:50 chance of survival in having the operation. The night before the operation whilst I was sitting at Derek's bedside saying our goodbyes, the consultant swept in trailed by his team of minions and said out loud to no-one in particular 'I am not prepared to put my team at risk' and walked out. It was the same consultant who had agreed to do it in the first place and had changed his mind less than 12 hours beforehand. He didn't even address us directly. We were discharged and just sent home to get on with it without hope.

22. At a subsequent admission to the MRI, I was taken to one side and told that Derek was dying, and I was told that I mustn't tell him. They said that there was nothing more they could do for him except to prescribe morphine. I went outside and just sat down on the steps of the Infirmary and wept.

23. I was told not to tell Derek that he was dying but I felt that he deserved to know. I had no counselling or support, neither of us did, and there was no counselling offered to me after he died. Telling Derek that he was dying enabled him time to come to terms with it and to put his affairs in some sort of order to include ensuring all the utilities and the like were put in my name so I didn't have the worry of it after he had gone. I did my best to continue with some form of normality for the sake of the children. Halfway through my daughter's 13<sup>th</sup> birthday, I took a call from the MRI to tell me Derek's death was imminent. I immediately left the party, leaving all the children with friends. When I came home, I had to break the news of Derek's death to my children.
24. Pneumonia was the named cause of death on Derek's Death Certificate as advised by the haematology department, because there was fear that a news reporter might uncover our story as death certificates are available to the public and our four children could be negatively impacted at school if AIDS was mentioned. There was so much fear, prejudice and intolerance about HIV/AIDS at that time. I was given a designated funeral director I had to use. He was flippant and insensitive to me. He was asking me what colour shroud I wanted when he interrupted himself and said 'You seem a bit upset' as if expecting the contrary.
25. My youngest stepdaughter has suffered with mental health issues since Derek's death as have I. My own children were deeply impacted not just as a result of Derek's illness and death but through my own struggles to cope and my subsequent diagnosis with anxiety and depression. In addition to my grief and trauma, I was very lonely. I felt pretty much ostracized by some of our former friends. As a young widow of just 37, you are, for some reason, seen by your married counterparts as a bit of a threat and I wasn't asked to join dinner parties and other events. I had a breakdown about 16 years later. I felt I couldn't carry on. I hit the booze and ended up in The Priory. When I first sought help from my GP, he said to me I looked seriously unwell due to

severe anxiety and depression. I had to take early retirement. I have been reliant upon antidepressant medication right up until just a few years ago.

#### **Section 6. Treatment/care/support**

26. I was never offered counselling or psychological support. As stated, when I was told that Derek was dying, I just sat down on the steps of the MRI and wept. I have been left traumatized.

#### **Section 7. Financial Assistance**

27. I received a lump sum ex-gratia payment of what I remember to be £70,000 and a lump sum payment of £20,000 split between the four children according to age through the MacFarlane Trust (MFT) a few years after Derek's death. A lawyer friend of mine helped me and I had no problem with the process. The MFT were helpful and I remember some additional advice about the tax and benefit related implications.

#### **Section 8. Other Issues**

28. As stated, I blame the Government for what happened to Derek. As far as I am concerned, they murdered Derek.

#### **Anonymity, disclosure and redaction**

29. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

### Statement of Truth

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

Signed.....  

**GRO-C**

Dated..... 28 January 2021