Witness Name: Patricia Harding
Statement No.: WITN5513001
Exhibits: WITN5513002 to WITN5513003
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF PATRICIA HARDING

I, **Patricia Harding**, will say as follows:

Section 1: Introduction

GRO-C My name is Patricia Harding. My date of birth is GRO-C 1951 and my address is GRO-C Suffolk GRO-C. I live on my own and I have two living children. Sadly, two of my sons have passed away.

2. I am making this witness statement about the effect and impact the death of my son, Lee Andrew Harding, from HIV had on me and my family. My son was born on GRO-C 1978 and he died on 8 March 1988.

Section 2: How infected

Haemophilia

3. Lee was my third child and third son and as a baby he used to bruise a lot. When he was around 11 months old, I took him to the doctors because I was

worried about the amount of bruising which he had. The doctor told me there was nothing wrong with Lee but I was not happy with this and I decided to take him to the Accident and Emergency Department at the West Suffolk Hospital. At first, the doctors at the hospital did not know what was wrong and I got the impression that they thought I had been hitting Lee so I asked them if that was what they thought. A doctor asked me how else could I explain the bruising?

4. Subsequently, Lee was taken to a ward and I was told that I had to wait outside. The doctors would not let me onto the ward and just told me that they would call me but I refused to leave and ended up sleeping in the chair outside of the ward. The next morning, no one acknowledged me, I was not asked how I was or informed me how Lee was. When a nurse came out of the ward, I quickly entered and I walked in to see Lee surrounded by people and he was on a drip. I asked 'what on earth is going on?'. A decision was then made to transfer Lee to Addenbrooke's Hospital where he was diagnosed with severe Haemophilia A .

5. Lee's main clinicians were Dr GRO-D and Dr Seaman (I do not know Dr Seaman's first name or initials). Dr GRO-D explained, but not very well, what haemophilia was. Shockingly, he told me that I should terminate any future pregnancies because there was a possibility that any other children which I had could also have haemophilia, which I thought this was quite rude. I should point out that I am adopted so I did not know I was a carrier of the gene, particularly as I had already had my two older boys who were not affected. In any event, I did go on to have my daughter but because of what Dr GRO-D said, I did not go to the doctors to inform them that I was pregnant until I was six and a half months along. I did not want them to tell me I should terminate the pregnancy.

6. Lee saw a number of clinicians over the years, including at our local hospital, [redacted] Hospital, where he might have the occasional check-up, but he was mainly treated at Addenbrooke's Hospital where Dr GRO-D and Dr Seaman oversaw his treatment. Addenbrooke's Hospital is an hour or so away from where we lived at the time. I had to learn to drive to enable me to travel to and from the hospital.

West Suffolk

7. From around 1979 to 1983, Lee was treated with Cryoprecipitate which was administered at hospital. From 1983, I administered treatment to Lee at home which I was trained to do. Initially, from around October 1983 to May 1984, Lee received Cryoprecipitate at home and then he was prescribed Factor VIII. When I started Lee's home treatment, I created a book in which I recorded the date and batch number of the Factor VIII which I administered to him **[WITN5513002]**. I recall that I was frequently attending the hospital to pick up new supplies.

8. In all of the time prior to Lee being diagnosed with HIV, I was never told about the risks of the treatment.

HIV infection

9. As you will see from my exhibit WITN5513002, there is note which says '14/3/84 Blood test (AIDS)' which is when I believe I had asked if Lee could be tested for HIV. I recall it was all over the news that haemophiliacs were being diagnosed with it. Also, by this time, Lee was becoming ill and I was concerned which is why I asked for the blood test. He had developed a constant dry cough, he used to have diarrhoea a lot and he lost a lot of weight. In my mind, he had all of the symptoms of HIV. Despite this, I was told that Lee could not have the blood test as it was not necessary. I asked and asked again for the HIV blood test but I was told that Lee was just run down or there was some other explanation for it. I felt like I was banging my head against a brick wall and that my concerns were being ignored.

10. I found out that Lee was HIV positive when I received a letter from Dr Seaman informing me that Lee had contracted the infection. Unfortunately, due to the passage of time and due to my ill health (I had a stroke last year), I cannot recall exactly when Lee was diagnosed with HIV but I do know that he had contracted it by the time he went up to middle school. It was not called HIV or AIDS at the time and I can recall it being called ARC (AIDS Related Complex). I was

absolutely horrified. I immediately turned the letter over and started writing notes and questions which any mother would do: is he going to grow up; will he be able to have a partner and children?

11. I went to the hospital and demanded an appointment with Dr Seaman who agreed to see me. She was so rude and dismissive. I had so many questions but she just said that she did not understand why I was asking her because there was more chance that Lee could get run over by a bus than developing anything from his HIV infection. Dr Seaman threw the letter in the bin and at the time I thought 'oh, actually that's my letter'. Dr Seaman was just not willing to talk to me, every question that I asked I was told was hypothetical.

12. I was under the impression that Lee was being treated with Factor VIII which was not imported but I do recall being given a batch of product which looked very different. I did use some of it because I had no other product left. I cannot remember if this was prior to or after Lee was diagnosed with HIV. It was in a wonderful box which had everything that you needed in it and I then saw the box on the television and I thought, that's the American product! I immediately called the hospital and said that I was not going to use it but they informed me that they had no other factor product. I then drove to the hospital and reiterated that I was not going to use it but they said that I would have to because there was not any other factor product available. I again insisted that I would not use it and told them that I would sit there until they gave me a product which had not been imported. It was all very unpleasant but eventually they took the box off me and gave me a different one containing UK product.

Section 3: Other infections

13. I found out just before Lee died that he had also contracted Hepatitis (I do not know whether it was B or C) but I was never told prior to that. During this period of time, clinicians treated you like you did not need to know anything and that they knew best and that I was not entitled to ask questions or query their decisions. I felt as though the doctors thought they were better than me.

Section 4: Consent

14. I was never asked for my consent in relation to Lee being tested for Hepatitis or HIV. If the doctors wanted a blood test, they took it. Lee could have had all sorts of tests and I would not have known as I could not be there 24 hours a day. I had to take Lee to hospital and take and pick up my other children from school therefore I was not able to always be with him.

15. I do remember the doctors telling me that they wanted to perform a lumber puncture on Lee and I told them that I was not happy about it because as far as I was concerned, they are incredibly painful. However, when I returned to the hospital on that day, Lee had undergone the lumbar puncture and he was upset about it because it was of course painful.

Section 5: Impact

Mental and physical effects of being infected with HIV on Lee

16. Lee's illness became worse and worse. He was like a skeleton and he was getting more and more rashes and lumps on his body. He developed lumps under his armpits, on his neck and in his groin which we called his 'peanuts'. At this point, I was called to the hospital for a meeting with Dr GRO-D and Dr Seaman and they told me that he had cancer all over his body and in his lymph nodes. This was about three months before Lee died. I cannot recall being told that he only had three months to live and up to this point I had been trying to get answers and trying to ascertain what could be done for Lee, but I might have been told about Lee's prognosis and I just did not want to hear it. I just knew he was really ill.

17. In the last few weeks of Lee's life, the hospital was giving him a number of blood transfusions and he said one day that he had a pain in his chest. I initially took Lee to the GP and had to wait to be seen. In the end, after a patient had left the treatment room, I barged in as I did not feel I had time to wait. The GP said that Lee needed a blood transfusion but there was not any hurry. By this time Lee could not walk and the GP walked out to the car with us.

18. I then had to go home to arrange care for my other children but because my husband would not help with child care, I ended up leaving the two older boys by themselves. I got Lee into the car and I rushed him to the hospital because I knew he was really, really ill. Again, I had to wait for a long time before anybody saw me and by that time, Lee had another rash coming up and his hair was falling out. He was in a terrible state. I recall that I was asked why it took me so long to get to the hospital but the hospital was an hour away. I remember that we had to go home before I took Lee to the hospital because he had asked for the lollipop which was in the fridge at home, he really wanted it but he did not eat it in the end. Lee had a heart attack and died that night and I was absolutely distraught and devastated. There was a nurse who I particularly liked and I remember that I hollered at her 'why didn't you tell me?' because in my mind, I had no idea that Lee was going to die. His Death Certificate states that Lee died from septicaemia, AIDs and Haemophilia A **[WITN5513003]**.

19. Despite everything that Lee went through, he lived his life to the full. He loved to play, especially with Lego. I did not wrap him up in cotton wool and he was quite active when he could be but he obviously got weaker as his HIV infection progressed.

20. We did get Lee a kitten which he called Ronnie. Ronnie would go to the hospital with us in the car in a pet box with his food and drink, Ronnie was his absolute life and they had such a close bond. Ronnie died within three weeks of Lee passing. The vet said there was nothing physically wrong with him but I think he sensed Lee had gone and he decided to go with him.

Treatment given for HIV

21. Lee was given AZT to treat his HIV infection which was a new drug. He received other treatments but I cannot recall what they were. I know he was given vitamins, paracetamol and the like.

Mental and physical effects of the treatments on Lee

22. Lee became extremely unwell after being treated with AZT to the extent that we had to go racing back to the hospital after he had received it. He had been given an adult's dose and the dosage was then rectified.

23. I do not know if the physical effects which Lee was suffering with were caused by his HIV infection or the treatment which he received for it but he had terrible night sweats – the mattress would be soaked. I would take him from his bed and wrap him in a blanket and put him into my bed whilst I changed his. He still had a continuous cough and then he would come up in lumps, bumps and rashes and he lost a lot of weight.

How infected status impacted on Lee's dental treatment

24. Once Lee was diagnosed with HIV, I was told in the letter (which Dr Seaman threw away) that I needed to inform his dentist, school etc. The dentist was really lovely about Lee but from what I can gather, his assistant did not feel that she wanted to work with him. The dentist's excuse was that he did not have the facilities to deal with Lee's teeth. I had to go to a dentist in Cambridge in the end, I was not allowed into the room with Lee and I used to have to sit outside and wait.

Impact on social, family and private life

25. My other children were only small when Lee started to get ill and I think that they felt pushed out to some extent. Notwithstanding that, my daughter was only 18 months younger than Lee and they were very, very close. Unfortunately, I had no choice but to focus on Lee and I certainly did not have social life. My husband did not help with looking after the children and child minding was very difficult. Even on the night that Lee died, my husband refused to look after the two older boys (my daughter was at her Aunt's) so I had to leave the boys at home.

26. My husband did not want anything to do with Lee. He was terrified he was going to catch something from him and he was too concerned about what his friends might think. After Lee passed away, I went to see a solicitor and arranged to divorce my husband.

Stigma

27. When Lee was diagnosed with HIV, my husband would not mention it or want to know anything about it. This was because he did not want people to know because of the stigma attached to it. I do understand because I had other children and they had been ridiculed by their peers because Lee had got haemophilia and at that time, haemophiliacs were automatically associated with people who had HIV whether they had been diagnosed with it or not. It was just not mentioned in the house. There was a lot of television coverage about people dying from AIDS and I would try to make sure that Lee did not see it, I did not want him to know that he could die.

28. Lee suffered so cruelly from being stigmatised because of his HIV diagnosis including in the hospital where he was being treated. An example is a junior doctor who had come to take blood from Lee had got two masks on and three pairs of gloves and I ended up taking Lee's blood myself because it was clear that this doctor did not want to go near him and I wanted to make sure that he did not hurt Lee. Lee picked up on the amount of protective equipment the doctors were wearing in the hospital and I had to tell him that it was because they did not want him to catch anything from them that could make him ill. The hospital also asked me to wear a mask and gloves when I was there but I refused to. At home I was dealing with Lee's sweat, sick and blood so I was not going to do that. It was a ridiculous request.

29. On one occasion, I remember that we had to go to the hospital when the Duchess of Kent was visiting the children's ward. Myself and Lee were pushed into a side room because the hospital did not want her to see Lee. We also attended the hospital sometime over a Christmas period and lots of presents were being given to the children. Lee quite innocently asked where his present was and he was told that because he was not an inpatient, he did not get one but he did not get the same treatment as the other children when he was an inpatient either.

30. I have so many examples of times when Lee was stigmatised, like when I arranged a birthday party for him and only one child came. It got to the point that people would cross the road to avoid you. It was horrific and I cannot really describe how awful it was.

31. My final example is that my second son came home from school and was really upset about the fact that one of his friends had taunted him about Lee being a haemophiliac and having HIV which Lee overheard. Lee then asked me if he had it and in a split second decision I said 'no – you haven't' and Lee in response said 'you wouldn't lie to me would you?' and my heart sank, I just could not see what could be gained from him knowing. I never told Lee that he was infected with HIV. How do you tell a child that they are dying?

Education/work/financial

32. After Lee's HIV diagnosis, I recall having a conversation with the Head Teacher of Lee's primary school who showed me his hands and referred to the cracks in them and asked what would happen if Lee coughed and his sputum went into the cracks. Lee used to sit at the Head Teacher's table but he was moved away in case he coughed on him.

33. Lee transitioned from primary to middle school in September 1987. He was only there for about five or six months before he died. He was absent from school quite a lot because he was getting ill but he would go when he was well enough. He was a very clever child but he did not like writing. He was very skilled at mathematics and did not understand why he had to write all of his workings out down to get to the answer when he could do it on his head.

34. Prior to Lee attending middle school, I was told that they would accept him provided that he had an ancillary helper. Lee did have an ancillary helper at primary school because he was sometimes confined to a wheelchair (as he had a lot of ankle bleeds) but she did not want to relocate schools and I therefore took that job although she still did one day a week at the middle school to allow me to have a day off. I helped with moving Lee around the school etc but I did not sit with him in lessons as I did not want to single him out from the other children.

35. I do remember that a P.E. Teacher at the middle school definitely did not want anything to do with Lee. He decided to make all of the children do forward rolls on a wooden floor and then he went over my head and wrote to Lee's hospital to say that he was not capable of taking part in P.E. and was basically excluded

from it. So instead, Lee would be given different activities such a collecting leaves or we would be in the gym and I would throw a ball to him. It was absolutely awful how he was isolated.

36. The middle school also told me that they would prefer it if Lee was taken home at lunchtime rather than staying at school for lunch so I used to have to walk him home, feed him and then take him back. It was never ending and I was exhausted all of the time.

37. After Lee died, I worked as a self-employed gardener for a number of years. By this time, I had divorced my husband and I had to keep the whole family going on what I earnt.

Section 6: Care and Support

38. There was an offer for Lee to have some home schooling but unfortunately my husband would not allow that. He was too concerned that it would mean that his friends would find out about Lee's HIV infection.

39. I was offered counselling. [The] Terrence Higgins [Trust] who I saw in the hospital came to speak to me about it but I did not take the offer up [redacted] For me, it was difficult to compare Terence Higgins' and Lee's situation. Lee was only a child and was not going to grow up.

Possible
Someone
from team

40. I did, however, have the help of a Family Support Worker who was very good.

Section 7: Financial Assistance

41. I really did not like asking for money and I cannot recall how I found out about The Macfarlane Trust but I did receive a payment of £20,000 from them. I instructed a solicitor to make the application because I could not emotionally deal with it at the time. In my mind it was blood money and after what Lee had been through during his short life, no amount of money could compensate for that. I am not a materialistic person and it did not matter to me if it was £1 or £1,000,000.

42. When the payment was actually received, I left it in the solicitor's client account for a long time. Half of it went to my husband as part of the divorce settlement but he was not entitled to it. He did nothing to look after the children or Lee. Eventually the solicitor wrote to me and I had to have it paid into my bank account but the majority of it sat there for years and years because I did not want to touch it. I always remember Lee saying to me that he would look after me when I was older and so I used some of the money to pay for the council house which I lived in as I thought that Lee would think that was his way of looking after me.

43. I received some assistance from The Haemophilia Society. They purchased one of the first personal computers that you could get for Lee and they also paid for Lee's funeral. We did raise a lot of money for The Haemophilia Society, sponsored events etc, some of which Lee did with us too.

44. I also received assistance from the Department for Work and Pensions for a short period of time in 1987 in the form of invalidity care allowance for Lee but it was means tested and because my husband worked (even though he did not give me a lot of housekeeping money) the payments were very small.

Section 8: Other

My bleeding disorder, treatment and exposure to vCJD

45. In [redacted] 1993 I had a hysterectomy in the West [redacted] Suffolk Hospital. At this time, it was not recognised that women could have haemophilia even though I had low clotting factor of only 25% (and if I had been male, I would have been diagnosed with haemophilia) but the hospital knew that I suffered with bleeding issues. I made it very clear that in the event that I needed blood product, I was not to be given Factor VIII because of what had happened to Lee and was told it would be okay as there were alternatives. When I woke up from the operation, I can recall that the doctor and the nurse were having some sort of disagreement over an injection they were giving to me but I drifted off back to sleep. When I woke up again, I asked what they were injecting me with and I was told that they had administered Factor VIII and that I had actually received two doses of it. After this, I was not given any more clotting products and I was black and blue down to my knees. I did not cause a scene but I was absolutely fuming.

46. After this, I received a letter informing me that I had been exposed to a batch of Factor VIII contaminated with vCJD and now if I have to have any sort of medical intervention, I have to disclose it which is horrible.

47. Any surgical procedure which I require has become very complicated. The hospital has to obtain plastic instruments which can only be used on me and are destroyed afterwards, which in turn can cause my treatment to be delayed. I also have to be the last operation of the day as everything has to be deep cleaned and/or incinerated.

48. In addition, because the instruments are plastic, they are not small enough to perform keyhole surgery so instead I have had to have open surgery in the past or decline the surgery altogether.

49. The other issue which I also now face because I have been exposed to vCJD is regarding dental treatment. My dentist refuses to do any tooth extractions for me and this has to be done at hospital.

50. I had a stroke last year, which given that my clotting factor is so low, is very unlikely. My daughter had to deal with the consultant and hospital at the time because they wanted to try a new medication. However, my daughter raised concerns with it after she had done some research because it can cause haemorrhaging and bleeding. My daughter had to insist that it was not a good idea and asked them if they had liaised with The Haemophilia Society about it. When the hospital reviewed the MRI scan of my brain, I had not had a normal stroke which is caused by a blood clot, I had had a bleed on the brain. I cannot help but wonder if this is related to being exposed to vCJD.

51. It is only very recently that a note has been placed on my medical records that I have a bleeding disorder (and I am not entirely sure that it is referred to as haemophilia) and that my clotting factor is only 25% although it does fall below that level.

Section 9: Conclusion

52. I was going to give my evidence anonymously because I have always wanted to protect my children and grandchildren from the stigma that Lee endured and I feel that there is still a certain level of ignorance which is of a concern to me. However, after discussing it with my family, I want Lee's story to be told and I do not want to hide his identity. In the time that Lee has been gone, I hope that opinions have moved on and I want Lee's suffering to be recognised and to get justice for him and all of the other children who died from this horrible disease.

53. I do not feel that the Government have done enough to put it out to the world that Lee and other children died through no fault of their own and because of the medical treatment which they received. They have tried to rectify it with compensation but where is the actual apology and explanation to the world? I

find it incredibly insulting because at the end of the day, who allowed this contaminated blood product to go mainstream?

54. Due to my ill health, I do not wish to provide oral evidence to the Inquiry but I would like my evidence to be read out in public.

Statement of Truth

I believe the facts in this witness statement are true.

Signed: ...GRO-C............................

Patricia Harding

Dated: ......24th April 2021.........................