Witness Name: Gayner Patricia Hallam
Statement No.: **WITN0467001**
Dated: 27 March 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GAYNER PATRICIA HALLAM

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 1 February 2019.

I, Gayner Patricia Hallam, will say as follows: -

Section 1. Introduction

1. My name is Gayner Patricia Hallam (previously, Gayner Patricia Green). My date of birth is GRO-C 1955 and my address is known to the Inquiry. I am currently married and not working.

2. I intend to speak about my late husband, David 'Dave' Green and his experience of being infected with human immunodeficiency virus (HIV), through Factor VIII clotting agent. In particular, I will speak about the nature of Dave's illness, how the illness affected him and me, the treatment he received and the impact it had on him and our life together.

3. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

Section 2. How Affected

4. Dave was born in 1948. He was a haemophiliac and I believe he was a 'Type A' haemophiliac.

5. Dave and I married in July 1983 and were together for nine years. We did not have children together. However Dave took on my son, Adam (born 1976), who was only small at the time. Dave was like Adam's father, even though they were not blood-related.

6. Dave was using Factor VIII when I met him. He had only just been put on Factor VIII. When Dave had been on cryoprecipitate, he would have to go to the hospital and wait for hours to be seen. When Factor VIII came out, it was like a godsend. He could treat himself at home and could stop a bleed before it got too bad. That was why it was so devastating to later find out its effects.

7. Dave would regularly visit Royal Sussex County Hospital for blood tests and to collect his Factor VIII medication. He injected himself on a regular basis with Factor VIII, whenever he felt he needed to.

8. On one occasion in 1985, he was called in for a regular blood test at the Haematology Department of the Royal Sussex County Hospital. He was not told what the blood test was for, as far as I can remember. It took six weeks for his test results to come through. When he went to get the results, he was told that he was infected with HIV.

9. Dave then came to where I was working. He told me that he had this incurable condition. We did not understand. It was called 'HTLV-III' in those days. He told me that I had to go and have a test. I asked, "What does this have to do with me?" He said that I might be infected as well.

10. I had to go and have a test and it took another six weeks for the results. In that time, Dave was really pulling his hair out. He thought he would have infected me. He said that he could not have lived with it, if I had

been infected. We went for my test results and they came back negative. We were not even sitting down in the doctor's room. We were just told - whilst standing up - I was negative, he (Dave) was positive.

11. We asked, "What did that mean? What do we do now?" They (the medical professionals) said that we have to keep everything separate – knives, forks, toothbrushes, towels and no sex. We were told that if you want to have sex, you need to have three extra strong condoms. We were not told much about it, because the professionals said they did not know much about it. We lived like that, everything separate, for a good year.

12. I had my own business at the time – a secretarial service. One of my clients was a gay man. He was the one who put me straight in terms of what HIV involved. His partner had been to the Louis Pasteur Centre in France (now known as the Centre médical de l'Institut Pasteur). He told us that we do not have to keep everything separate. He said that Dave is the one who is at risk, it is not the other way around. He sat with us for a long, long time. He had been given different information over in France. They were more up to date about the virus over there than in England. Never did a medical establishment in the UK give us any sort of advice like that. After receiving that advice, our lifestyle did relax a bit.

13. Dave was OK initially and we carried on, but then he started getting poorly. Over the next few years, his health deteriorated. About four years after the diagnosis, in 1989, Dave went to the Haematology Department as normal. I got a phone call and was told that Dave had been sent up to a hospital in Hove.

14. I went to a fete that afternoon with my son. When we came back, Dave was still not home. We phoned the hospital and asked if he was still there. I was told that he would be kept in overnight. I told them that I would not be up to see him. The next day, it came to tea time and Dave was still not home. The hospital was really off with me – they kept

asking why I was not coming up to see Dave. I said that I have a son at home and asked them if Dave was coming out. The hospital said no. I said, "But he's got work tomorrow. What's going on?" I told them I would come up to the hospital tomorrow, after work.

15. The following day I went to work and then straight to the hospital. Dave had a private room on Ward 6. You could not get into the ward. Instead, there was a bell. I pressed the bell and a nurse came out. I told her who I was. I thought that this was all strange. All the other wards I had passed were open. I went into the room and they said the doctor would be in soon.

16. I was in there with Dave, telling him about the day at the fete and not thinking too much about the situation. The doctor then came in and said, "He's got full-blown AIDS." I did not say anything. I got up and walked out. I do not even know how I got home. I drove to my mum's and was just in tears. When I got to my mum's, she took my hand and asked, "Didn't you realise?" I said, no. It was like a bombshell.

17. I knew it could happen, but I was in denial. Because it took four years to get to that stage, we had just gotten on with our lives. Although I knew it could happen, I just thought, it would never actually happen.

18. Ward 6 was the AIDS ward. That was why you had the bell to get in. There were six rooms in there and everyone had a private room. I was in and out of that ward so often. I would sit up there all day with Dave and take my knitting with me. There was a little kitchen there. I would take food to put in the microwave, make teas and coffees etc.

19. When I first spoke to the staff there, they thought I was so cold, because of the way that I initially was – because I had not gone up to see Dave immediately.

20. Dave later kept going down with PCP pneumonia. He developed other things later – Hepatitis C and much later on, diabetes.

21. Dave died at home on 22 October 1992.

Section 3. Other Infections

22. To the best of my knowledge, I do not believe that Dave received any other infections, aside from HIV and Hepatitis C as a result of being treated with infected blood products.

Section 4. Consent

23. As mentioned above, I do not believe that Dave knew he was being tested for HIV when he received a routine blood test. I do not really know how we would have liked to be told about his diagnosis. We would have liked more information, but the medical professionals said they did not have any more information.

Section 5. Impact

24. Dave described the impact and effect of HIV as "like a timebomb waiting to go off." After Dave was diagnosed with full-blown AIDS, both Dave and I had to give up work due to his diagnosis. Dave had previously been a tailor. One minute we had two incomes and the next minute, we were on social security.

25. I had to go to the bank and lay out our position. In those days, you had a bank manager that you knew. The bank manager gave me a loan to cover all our payments with hardly any interest on it, because I had told him exactly what was going on. It was also coming up to Christmas and I had told the bank manager about my son looking forward to getting a bike. The bank manager said, "You'll get a loan and there'll be enough in there to get a bike."

26. I became Dave's full-time carer. I had previously given up my own business and was working for the South Eastern Electricity Board. I

had a pretty good job there. It was nice, easy and well-paid. But I had to go in and give my notice in order to care for Dave.

27. Over the next three years, Dave was in and out of the ward.

28. On one occasion, I took Dave out shopping whilst he was in the wheelchair. The supermarket was only around the corner and it was fairly big. Dave went into a hypo (hypoglycaemia) when we were in the shop due to his diabetes. He said he felt strange so I thought his blood sugar had gone down. I knew if his blood sugar went down, he had to have some sugar. But it was too late. He threw his head back, his eyes rolled back and he let out this horrific roar. I thought, oh my God, he's just died. I was screaming, "Help me, help me." I didn't know anything about this hypo stuff. There was a woman who was diabetic who worked at the supermarket. She went to give Dave something with sugar in it. I just grabbed it off her and said, "I'll do it, I'll do it." I went to give him that, but he could not take it. We called the ambulance. When they came, they weren't putting gloves on and they were going to inject Dave. In the middle of the shop I had to shout, "Put gloves on." They looked at me and I said, "AIDS." It was little things like that, that you should not have to think about. You have got to be careful about what other people are doing and not just what you are doing.

29. We had to tell my son, Adam, what the problem was with Dave. Adam would have been about 13 when Dave was told he had full-blown AIDS, however we told Adam before that time that Dave had HIV. We could not have open cuts anywhere on our bodies. Adam knew from an early age that he could not tell people. He would tell people that Dave had cancer. We taught Adam how to lie.

30. There was a big stigma regarding HIV. The decision not to tell anyone was made as a family. We could not tell anybody; we did not dare tell anybody. We were afraid of reprisals, of being chased out of our home. We were living in council property and it was not a very good estate.

31. We were only living on that particular council estate because when Dave was first diagnosed, we were in the middle of trying to buy our first property. We were getting the mortgage sorted out and then Dave got the diagnosis and we could not get life insurance – neither of us. So we had to forget about that and stay in the council property. It totally screwed up all our plans. A couple of years later I went on the radio and spoke anonymously about the fact that I knew how to be around someone with HIV; I knew how to protect myself and so was less at risk of being infected than others, yet still the insurance companies would not give any insurance cover to anyone like me who was associated with someone diagnosed with HIV or AIDS.

32. The medication Dave was on – AZT – was so toxic. He could not do anything. He would come down in the morning, get on the sofa and sleep. He was also vomiting all the time. In the end, he said he could not take it anymore. Some people who took AZT were OK, but for a lot of people, it was so toxic, it was unbelievable. Dave had no quality of life at all when taking AZT.

33. As mentioned above, Dave died at home. We knew it was coming. He was in a wheelchair by then. He was in a lot of pain. The hospital were not managing his pain very well. I was giving him morphine at home. On one occasion while I was pushing Dave in his wheelchair from the front room to the bedroom, he looked up crying and with tears, saying "Why don't you take me now? Just take me now."

34. There was a chest of drawers at home where the whole top drawer was just full of medication. By this time, I was injecting Dave for the diabetes and with Factor VIII. There was nothing else to use. That's what I was doing all day, giving him pill after pill, injection after injection.

35. The last time Dave went into hospital, they were going to give him more pills. But he said he had had enough. He refused all treatment and they sent him home to die.

36. The night it happened was a few weeks after they sent Dave home from the hospital. I sat by him that evening. Dave had lost so much weigh by that point that he had gone to nothing. He was skin and bone. He turned around to me and said, "I haven't got long now. I feel it." That night he started making funny noises. I went to get him some water but he could not take the water. He was not with it. Adam came into the room. I was laying on the bed with him. Adam was holding Dave's hand. When Dave eventually went, Adam would not let go of his hand. He said, "He's not gone, he's coming back." I had to pull Adam away. Adam was 16 when Dave died. It was a harrowing time.

37. At the time of Dave's death, Adam had only just returned home after running away because he could not cope with it all. Adam had been out of the family home for around 18 months. He was staying with friends, in cars – that's what I heard. I had been in touch with social services but they would not help. They said he will sort himself out. I also had the Education Authority on to me – they were going to fine me £1000 because of Adam missing school. I told them that I could not do anything about it and that I was having to care for my terminally ill husband 24 hours a day.

38. My mum eventually managed to find Adam and took him to her place. He would not come anywhere near us (Dave and I).

39. Adam started taking drugs during the period of Dave's illness. I did not give him the attention that he was craving. As a mum, I blame myself. I feel guilty. The night after Dave died, Adam went out and caused a lot of trouble. He was kicking off about the government killing his father and the police picked him up and put him in a cell. The police phoned me and asked if his father had just died. I said yes. They said they would not charge him and asked me to come and pick him up. Adam had so much anger in him. I knew that Adam started on drugs because he was trying to find some relief from the situation.

40. Adam tried to sort himself out over the years. Although he got married, it didn't last. He just could not seem to sort himself out. He would phone me and would still be going on and on about what happened. I had always thought that once Dave was gone, I could give Adam the time he wanted. But it was just too late. The damage had been done. Adam later heard his wife was seeing someone else. On one particular night, he took a load of drugs, then he went to this place and a fight occurred. Adam was restrained and he ended up with brain damage. He passed away 3 weeks later in GRO-C 2012. At the inquest, they put it down to misadventure. No criminal charges were laid against the people who restrained him. People thought that he was volatile, but Adam was sensitive. I knew that. He just never recovered from his anger.

41. My family life, my family unit, was greatly affected by Dave's situation. I read a lot and sometimes I will be sitting reading, and something I read will trigger a memory which will then take me back in time to my little family unit that I once had, but is no longer there. I then find myself getting depressed even now all these years on.

42. Dave and I made friends with a lot of other people who had HIV, through a support group called Open House (which is described in more detail below). Later on, when I'd met my current husband, we were looking through my old telephone book and my husband was reading out names of friends Dave and I had made through this group – they were mostly all gone. We were going to two, sometimes three funerals a week. It got to a stage where we were fitting in shopping around the funerals. That was the life we were living. Basically, it was just death.

43. It helped a lot when I met my current husband. Dave had already said to me that I should carry on with my life. He said that he did not want me sitting there, moping about him. He said I was to go out and meet somebody and make sure they're a nice person. I met my current

husband in May 1993. We just clicked. We got married in 1994. I felt I could re-marry because Dave had given me permission.

44. Sometime just after the summer of 1993, my whole body shut down. I had previously lost a lot of weight. I had gone down to about 5 stone. I could not eat. My local doctor was going to send me into hospital and drip feed me. He had put me on build-up drinks to try and get my weight up. I had held myself together all that time, but then I just went down like a ton of bricks. I had been working in the markets and had become very brown. The hospital thought that I had been abroad and thought that I had caught something. They tried antibiotic after antibiotic. My temperature was off the scale. In the end, they tried one last antibiotic. They put it in a canula and had to wake me up every three hours for treatment. Whatever it was, it worked. However no-one could ever tell me what the diagnosis was. I thought it was probably due to my body finally reacting to all the emotional trauma of the past few years and it simply closed down.

Section 6. Treatment/Care/Support

45. As previously mentioned, the stigma around HIV at that time was very bad. On one particular occasion, Dave had to go to the Ear, Nose and Threat (ENT) department. They put him in a room on his own. He had his own towel, cup etc. The staff hardly went in to see him. When Dave came out he said, "I feel like a leper. No one came in to talk to me."

46. Dave and I found a support group called Open House (mentioned above), but it was not to do with haemophiliacs – it was a gay group. It was run by a gay vicar called Marcus, in the middle of Brighton and we used to go there a lot. There were some druggies there, but mostly it was gay men. They would put on a lunch for everyone, around a great big table. There was a living room upstairs. If you had any problems, you could talk amongst yourselves or you could talk to the vicar.

Marcus handled all the funerals. He eventually handled Dave's as well. We went there a lot because we needed the support. You were very isolated because you could not talk to people about it.

47. A friend of Dave's, who worked high up for the government, told us about the heat treatment of Factor VIII. He said to us that Factor VIII was heat-treated up to a certain level, but due to cost, it would not be treated up to any higher level. We were told that if that had been done, it would have eradicated all of the virus. I cannot remember who this friend was, it was so long ago. All I remember is that it stuck in my mind. That's why we always thought it was a cover-up.

48. When I lost Dave, I had access to Cruse Bereavement. Open House got in touch with them and I had counselling there, which got me through that period. When I lost my son, I had no counselling. Absolutely nothing. I went to pieces.

Section 7. Financial Assistance

49. We were never contacted about any available financial assistance through a fund or trusts scheme.

50. We were however contacted by some solicitors up in London – I cannot recall their name. There were solicitors in Scotland, Wales and London. Dave was not too ill at the time and so we went up to London. It was just us and the solicitor in an office. We were told that we would be taking the government to court for loss of earnings along with physical and emotional suffering and that we could expect to get a minimum of £250,000. That was a lot of money back in those days.

51. They were supposed to be doing that for all the haemophiliacs who had been infected by blood products. Everything seemed to be progressing OK. A couple of years later, they called a meeting for all the infected

haemophiliacs in the London area. A lot of haemophiliacs had died in the meantime and a lot were incapacitated. When we got to the meeting in London, there was a load of people there. The solicitors stood up and said – "We are so, so sorry, but we have to tell you that the government has tied your hands behind your back. Most of you are on legal aid. The government have put together offers. But if you do not take the specific offer for you, all your legal aid will be taken away." For an infected child, the offer was £9000. For a single man, the offer was £15,000. For a married couple, the offer was around £30,000 or £32,000. For a family, the offer was £60,000. We got the £60,000. But that was nothing compared to what we were supposed to have received. That did not even cover the loss of earnings. £9000 for a child? I thought that was disgusting. They put it up on the television – all these haemophiliacs getting a pay-out. It sounded good. It was not.

52. With that money, we bought a nice comfortable bungalow and Dave was happy there. It was in GRO-C, just outside of Brighton.

Section 8. Other Issues

53. Dave had been the claimant in terms of social security and I was dependent on him. As soon as Dave died, I had no money coming in. I was told that because I was now a new claimant, that I could not make a claim for six weeks and had to fill out a new form. One of my friends filled in the social security forms for me because I couldn't face doing it. Then I was told that because my son was between 16 and 18 years I was unable to get any money for him. That is why within three months I was out working on the markets. I took my son, so that we both had work. I did not have a choice.

54. I was told that I was not entitled to a widow's pension because my son was over 16 and because I was too young.

55. As far as I am concerned, the government gave Dave this problem, the government killed him and then at the end, I could not even get any money to survive myself.

Statement of Truth

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

Signed GRO-C

Dated 27 March 2019