Witness Name: Sheila Squires
Statement No: **WITN4641001**
Exhibits: **WITN04641002-007**

Dated: 30 September 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF SHEILA SQUIRES

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 28 September 2020.

I, Sheila Squires, will say as follows: -

Section 1. Introduction

1. My name is Sheila Squires. My date of birth is GRO-C 1937. My home address is known to the Inquiry. I am retired and live with my husband Michael. We married in 1956 and had two children, Peter born in 1961 and Dawn in 1964. Before I had the children, I worked for Trico's – a factory that produced windscreen wipers. I have three grandchildren, two boys and a girl.

2. I intend to speak about my late son Peter Squires, who was born on GRO-C GRO-C 1961 and sadly passed away in 2000, at the age of 39. Peter was infected with HIV and Hepatitis C (HCV), as a result of being given contaminated blood products to treat severe haemophilia A.

3. In particular, I intend to discuss the nature of his illness, how the illness affected him, the treatment received and the impact it had on him and our lives together.

4. 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.

5. My husband Michael Squires assisted me with my statement. His date of birth is GRO-C 1937 and he is retired. He used to own a sheet metal factory.

6. We are very vague on certain aspects of Peter's treatment and dates may not be correct, but I exhibit medical records from the Royal Free Hospital. I never received medical records from Great Ormond Street Hospital. As an adult, Peter was very quiet about his condition, preferring to deal with it himself and as a result we knew very little about what was happening.

Section 2. How Infected

7. Peter was born on GRO-C 1961 at GRO-C Maternity Hospital – part of the West Middlesex Hospital. I remember he was bleeding from the naval after the birth and was rushed away. I was later told that it was to do with the umbilical cord and nothing to worry about.

8. By the age of 7 months he was able to stand and ended up hurting his ankle. I took him to my local clinic, but they could not do anything and advised that I took him to West Middlesex Hospital. Peter was kept in and I was told there was a possibility that he had haemophilia.

9. I had no idea what haemophilia was at the time and asked the nurse if it was similar to leukaemia. She explained that it was not a cancer of the blood, but where the blood has a missing factor. She went on to say that members of the Russian Royal Family had the condition and there was no cure. I was just told to keep an eye on Peter.

10. As far as I am aware there was previously no history of haemophilia in my family – my Gran was alive at the time of Peter's diagnosis and remarked that there were no diseases in her family and was very dismissive. The doctor wanted to see my parents to determine if there were any genetic conditions, but they did not want to know. It was as though there was some shame attached to Peter's condition.

11. The haemophilia meant that Peter was always covered in bruises and he would even get marks from the straps on his pram. Before Peter was diagnosed, medical professionals often thought I was battering him. I can recall one occasion at West Middlesex Hospital, where I was not allowed to go near Peter and a nurse had to be present. Once they knew this was not the case, they could not have acted any more differently and were very helpful. All the same it was hurtful that they thought that I may have been mistreating Peter.

12. At first there was no treatment available for haemophilia. Peter was a very adventurous boy and did not hold back, neither did we wrap him in cotton wool. Therefore, he would have joint bleeds and he would have to lay in bed. He once had a lump on his forehead, caused by a bleed and experience blindness for a couple of days, as the blood would drain into his eyes.

13. Pre-cryoprecipitate, medical professionals did not know what to do with haemophiliacs. My husband recalls Peter falling over and biting through his lip whilst we were at a party in GRO-C He was only 4 at the time. We took him to St James' in Balham because it was the closest hospital, but they could not do anything. We then tried GRO-C Hospital, but again they could not treat Peter. He was finally seen at West Middlesex Hospital.

14. At the back of West Middlesex Hospital there was a special ward, not commonly known about. It had children in with physical disfigurements who had seemingly been hidden away. Peter was shoved away in that ward and tied to the bed. He was put into a nightdress and the cords were tied to the

bed so he could not move about. My husband and I remember him screaming when we left.

15. When Peter was 6, Dr Dormandy at Great Ormond Street, told us about cryoprecipitate – a new treatment available for haemophiliacs. She asked if Peter could receive the product. I remember saying that he could have anything that would help the condition. She came out to visit us with her assistant, at our home in GRO-C

16. Peter received cryoprecipitate at Great Ormand Street Hospital and we would have to take him in whenever he had a bleed. On average, he would have a bleed once or twice a week that required treatment. It used to take 2 hours for the cryoprecipitate to be administered, as it had to be defrosted and the top part of the product had to be separated before the nurse could inject it. It used to be referred to as the 'top of the milk'. If Peter had a particularly bad bleed, he would be kept in hospital overnight or for a couple of days to receive further product.

17. My husband recalls how Peter would never mention about a bleed until he went to bed. We used to leave our bedroom door open at night so that he could call out to us and if he required treatment we would ring the hospital in advance, so they could prepare the cryoprecipitate.

18. As a direct result of being a haemophiliac, Peter did not start any education until he was 7. He attended a handicap school on GRO-C until the age of 12. Our local school would not accept him as a pupil because a lot of their classrooms were upstairs and they did not want to be responsible if he fell and hurt himself. He would travel to school by coach and was picked up from our house.

19. Peter used to pluck his eyelashes out because they were lovely and long. I mentioned this to the doctors at Great Ormond Street and they arranged for him to see a psychiatrist. During the consultation, we found out from Peter that the psychiatrist was trying to find out if there was any domestic violence in the family, as he thought this was the reason he was removing

his eyelashes. I told the doctors to never let my son near that psychiatrist again or I would sue the hospital. Peter was never seen by him again.

20. On another occasion they wanted to do a brain scan on Peter, but I refused because I knew there was nothing wrong with his brain.

21. Once Peter was 12, all of his haemophilia treatment was moved to the Royal Free Hospital. Usually children are transferred from Great Ormond Street at the age of 11, but they kept treating Peter for another year because he was not very tall and they could get away with it.

22. My husband, along with doctors at the Royal Free Hospital, were keen for Peter to attend the Lord Mayor Treloar College in Hampshire. I did not want Peter to go away from home, but my husband felt that it would make him more independent. I must admit it did do him good and he made a lot of friends, who were naturally all haemophiliacs and so they had a common bond. Peter's character was tender and he was always willing to help people and I think it was because he went to that school. My husband saw Peter pushing another boy in a wheelchair when he first went down to visit him.

23. Peter attended Treloar's from 1973- 1978 and had some good times there – he enjoyed sports and even learned to gamble, there was a bookmaker down the road.

24. My husband and I were not told anything about Peter's treatment whilst he attended Treloar's. As far as we were concerned, he was still receiving cryoprecipitate and we were not told any different. They never used to ring up when he had a bleed and we would only be aware if Peter mentioned it. We did not feel the need to question the school, because a Matron was present and all treatment was overseen by Oxford Hospital.

25. In the 5 years he attended Treloar's, we never had any consultation with a medic and no one ever provided an update on Peter's treatment and condition. If he had remained at home, we would have regularly seen

doctors at the Royal Free Hospital, yet we were never consulted about anything whatsoever. I suppose that seems strange now that we did not enquire but in those days you just trusted that the medics and the health service knew what they were doing.

26. Peter used to come home every fortnight for the weekend. Michael would pick him up on Friday evening and drop him back on the Sunday. He was always fine about going back to school and my husband even picked up a couple of his friends on the way home. By the age of 15/16 the school allowed the boys to travel home on the train. I do not recall Peter bringing Factor VIII home and if he had a bleed, we would take him to the Royal Free for treatment.

27. I only became aware of Peter using Factor VIII after he left Treloar's – he came home at 17 because he wanted to go into electronics. Peter did not tell us about Factor VIII and how long he had been taking it for.

28. Peter would get the Factor VIII ready on his tray and administer the product himself, but if he struggled to find a vein, my husband would help him. At the time, I thought it was good that the product could be used at home and it saved us many trips to the hospital.

29. Sometime after Peter left Treloar's, he told me that he was HIV positive. We were watching a television programme together about a haemophiliac and I commented how it was awful that he also had HIV. Peter replied 'so have I'. He went on to say that he would not live to an old age.

30. My husband and I never attended any consultations with Peter about his HIV infection and he never communicated anything to do with his treatment. I was never given any information about infection management control.

31. I knew that Peter went to the Royal Free Hospital for a trial and was under the care of Patricia Lingley – she had a number of haemophiliac 'boys'. I do not know what the trial was for and Peter never spoke about it. He never wanted to engage in a conversation on the subject and I did not want to

bombard him with questions. The hospital could not provide us with any information unless Peter provided them with consent to do so.

32. At one point, I asked at the Royal Free if Peter had hepatitis C but they said no, yet this contradicts what is written in his medical records.

33. I asked for Peter's medical records after he passed away, but the Royal Free were rather reluctant and said that I would not understand them. Eventually we were given copies by Patricia Lingley and this is when I first became aware of his HCV infection. At the time we were given the documents, she mentioned that only one of her 'boys' was still alive.

Section 3. Other Infections

34. To my knowledge, Peter did not contract any other infections apart from HIV and HCV as a result of receiving contaminated blood products.

Section 4. Consent

35. As parents, we sent Peter to Treloar's in the faith that they would treat him correctly. When he arrived at the school he was on cryoprecipitate, but when he left he had been switched to Factor VIII. In those 5 years we were never asked for consent, or informed that his treatment had changed.

36. I do not recall signing anything when he started at the school and whilst he was a child, we still had authority over his treatment and welfare.

Section 5. Impact

37. I was not aware of Peter's liver problems and associated health issues before reading his medical records and I am unaware whether his HIV infection progressed to AIDS.

38. Not long after Peter was diagnosed with HIV, he was asked to take a trial medication. A number of his haemophiliac friends were also asked. One was a laboratory assistant and knew more about the medication, but they all refused.

39. Upon reading Peter's medical notes, I have discovered that he suffered with depression. My husband and I were not aware of this at the time and he never showed any signs of depression.

40. To us, Peter always made the best of his life. He never stayed in bed because of the infection and would not let anything stop him. He loved sports and would often go and watch GRO-C play. In the summer he used to play tennis with a colleague after work and he often went to the bookmakers. He was very proud of his car and would change it every couple of years.

41. I feel awful that Peter could not confide in us at the time. This could have been part of his coping strategy or he may have been told to keep quiet because of the stigma attached to the virus.

42. The virus slowed Peter up and there was a visible decline in his health. As he deteriorated he went off food and consequently lost a lot of weight. I remember he would often eat McDonalds because he could not stomach anything else.

43. We spent the Christmas before Peter passed away at Center Parcs, with all the family. Every now and then Peter's knee would play up and after walking his new-born niece around the resort, he complained of feeling unwell. He made the decision to go back home and Michael drove back with him.

44. Not long after the holiday, he went into work over a weekend because they had a job to finish. This was the only time he ever did overtime and was a

week or so before he died. Despite his ill health, he had taken the trouble to go into work.

45. Peter never wanted to go into hospital because he thought he would never come out. He had seen a number of his haemophiliac friends pass away whilst in hospital. Whilst Peter was visiting a friend, his mother remarked she would make his favourite pudding for when he came out. Peter came home angry, saying 'does she not realise he will never go back home.'

46. In the days before his death, Peter was supposed to have another liver biopsy. He was not well at all and had been coughing up blood for a couple of days – we did not know anything about this because he did not tell us and kept everything to himself.

47. Peter's health deteriorated further, on the evening of GRO-C 2000, I told my husband to take him to the hospital. He said he would take him in the morning. During the night Michael heard Peter and went in to see if he wanted anything. He got Peter a glass of milk, put it on the cabinet in the bathroom beside where Peter was sitting, on the toilet with the lid closed.

48. The next morning, I found Peter unresponsive and slumped on the toilet. We phoned the emergency services and when the paramedics arrived I asked if they could move Peter to the bed, but they said that they could not move him until the police had arrived. The police wore masks and gloves and were later criticised by the coroner for how they treated a HIV victim. The undertakers took Peter away after he was pronounced dead.

49. Not long after he passed away, St Thomas' hospital phoned up to ask for a liver sample. My husband consented to this and further remarked that the NHS had caused Peter's death by injecting him with contaminated blood products. They concluded that he died of liver damage and would have required a liver transplant.

50. The funeral parlour did not want us to see Peter but my husband insisted that we did. He had been kept in a black bag, had blood spots on his face

and was very cold to touch. I asked if they could dress him in his clothes, but they said they were unable to touch him because of the HIV.

51. The funeral was held 4 weeks after Peter passed away. We chose a cremation and never asked about a burial.

52. Peter was not able to have a house or a family of his own because of his HIV infection. He often commented that he pulled the short straw, but he thought it was not worth buying a property or getting married because of his reduced life expectancy. Whilst the virus certainly stopped the natural progression of his life, he still had a couple of relationships and I am still in contact with one of his girlfriend's now.

53. Peter still came on family holidays, but one time he ended up being hospitalised in Spain. We were also meant to go on a cruise, but the doctor on board would not take Peter as a patient because of his haemophilia – this had to be cancelled.

54. I hated every minute of Peter being at Treloar's because he was so far away from home. I was so pleased when he eventually moved back.

55. Most of Peter's friends from Treloar's have died as a result of the blood products they received.

56. I did not go around telling people that Peter was HIV positive, but all of our close friends were aware. They were fine with him and did not treat him any differently. As far as I am aware, he never suffered any stigma because of the virus.

57. Peter was never embarrassed about his HIV infection and he even was interviewed on the subject by the BBC.

58. Peter never used to let me clean his medical tray because he did not like me touching his blood – this never bothered me because he was my son.

My husband also continued to use the same towel as Peter, to show solidarity with him after his diagnosis.

59. Peter became a medical instrument assembler at the age of 18 and worked in this role right up until he died. The company were aware of his HIV status and were very good if he ever needed time off for appointments or due to ill health.

60. Peter would often drop a few people home after social events at work, but all of a sudden one of the women turned on him. She said to the charge hand that Peter should not be working there because he was on crutches.

61. Peter worked consistently throughout his life despite having a limp and difficulties walking. He always took his annual leave during horse racing weeks.

62. Once his health deteriorated, I felt as though I was living a death sentence for Peter. I used to comment that it was like being on death row, just waiting for the inevitable to happen. Towards the end, each morning I would think it could be his last day.

63. When Peter died, I wanted to go with him and since his death, I feel as though I am not living anymore, just existing. I think all three of my grandchildren have kept me alive, otherwise I would not be here now.

64. Since Peter's death, my husband and I have never really spoken about what happened so I am not sure how he feels about everything.

65. My daughter has never openly discussed the effect of Peter's infection and death or her life and I do not want to bring it up for her. I am not sure if she has spoken about it all with her own children.

66. GRO-C and I were both diagnosed as carriers of haemophilia GRO-C GRO-C Dr Dormandy had moved from Great Ormand Street to the

Royal Free and asked if we both could be tested. We had to go in for a couple of days and files were taken from us both.

67. When my granddaughter was 11, I asked for her to be tested GRO-C GRO-C. The hospital refused because of her age and said we would have to wait until she was 16. I thought this decision was ridiculous and said that she could have a child by that age. One of the nurses agreed with me, but I was shut down.

68. My grandsons GRO-C GRO-C The eldest is 26 and the youngest is 23.

Section 6. Treatment/Care/Support

69. My husband and I have never been offered any counselling or psychological support via the NHS in relation to my son's infection with HIV and HCV.

Section 7. Financial Assistance

70. Peter applied to one of the funds for financial support and received a one-off payment of £20,000.

71. I have also received some money from the Skipton Fund, but cannot remember how I became aware of their existence. After Peter had died I received first £20,000 and then about a month or two later I received £50,000. I cannot specifically remember what that money represented though it was clearly as a result of Peter dying. I do not remember applying for this money, maybe it was someone at the Royal Free. My memory is very vague on this.

72. The MacFarlane Trust (in conjunction with the Haemophilia Society) arranged bereavement counselling for my husband and I. We attended the

sessions for a year, but felt that it did not help us. Our group consisted of women who had lost their husbands – we should have been treated differently as we had lost a child.

Section 8. Other Issues

73. My husband and I used to attend an annual memorial service for the haemophiliacs that have died as a result of the contaminated blood scandal. It was initially run by Reverend Tanner GRO-A and his family. We do not go anymore because the Haemophilia Society has introduced ticketing for the event and they stopped the haemophilia nurses from attending.

74. The government killed my son by allowing the use of contaminated blood products that we had no knowledge of, having put our trust in them, this should never have been allowed to happen.

75. I would like the Inquiry to find justice for the boys that are still alive, but I have my doubts over whether that will be achieved.

76. In order to draw attention to the plight of Haemophiliacs who have been infected with HIV/AIDS contaminated Factor 8, I have written numerous letters to MPs including Neil Kinnock, the then leader of the opposition and Michael Portillio, Secretary of State for Health, Kenneth Clarke and Prime Ministers including Margaret Thatcher and John Major. I never received satisfactory responses and what I did receive in reply was always written by a member of staff. In the main my impression is that the government at least was very wary about accepting blame for fear of paying out beyond that set aside for the trusts such as McFarlane and Skipton. Compensation was never the point of my letters, it was recognition and acceptance of what had been done to haemophiliac boys like Peter. I have kept copies of my letters and the responses should the Inquiry wish to see them.

77. I do however exhibit the following documents:

WITN04641002

I exhibit a document "Statement of Peter John Squires" that I found among papers in Peter's belongings. As indicated by the heading this is in Peter's own words. I do not know for sure what this statement was for but it may have been to do with some legal action, which never came to anything.

WITN04641003

I exhibit a document dated 9th March 2000 after Peter's passing. It is written by Nalina Patel from our GP practice and it is exhibited because it certifies Peter's death on GRO-C 2000 and identifies that Peter was diagnosed with NonAnonB hepatitis in 1980. it also identifies that Peter had HIV, Hepatitis A & B though no date or year is specified for those diagnoses.

WITN04641004

I exhibit a page from Peter's autopsy report. Within the report's case history, it is identified that Peter was diagnosed with HIV "in the early eighties". It also states that he had cirrhosis of the liver.

78. The following exhibits are taken from Peter's medical notes obtained from Royal Free after Peter passed away. I exhibit those documents thought by the inquiry investigator to be most relevant. All of these notes are a long way post diagnosis being late nineties and generally refer to his routine visits connected to HIV/HCV/liver, HIV treatments and trials, including the "Quattro Trial", to which he apparently consented and problems he was having with his knee, which had been replaced. I will retain all of the notes.

WITN04641005

A letter from Eleanor Goldman, Haemophilia Centre Royal Free Hospital to Dr Geoff Dusheiko Consultant Hepatologist at The Royal Free. dated 9 May 1995. in the first paragraph the letter states that Peter was "exposed to hepatitis C early in 1974".

WITN04641006

A letter from Christine Lee (CL) Professor of Haemophilia at Royal Free Hospital to Dr Debbie Large, Coroner's officer, Coroner's Court London N8 7PY. In this letter dated 1st February 2000, CL gives a summary of Peter's history there. Within this letter in the first paragraph, it is stated that Peter was infected with hepatitis C "-probably in 1979, as a result of receiving large pool clotting factor concentrate and he was infected with HIV in 1983". the letter goes on to say that Peter had cirrhosis of the liver secondary to his HCV infection. His last attendance at the haemophilia centre was exactly one month before he died.

WITN04641007

A page from Peter's Autopsy report that gives the conclusion that the cause of peter's death was:

- gastrointestinal haemorrhage
- HCV cirrhosis of the liver
- HIV infection
- pneumonia.

Statement of Truth

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

Signed GRO-C

Dated 30th September 2020.