Witness Name: P L Merry

Statement No: WITN0724001

Exhibits: WITN0724002-9

Dated: March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF

PHILIP LAURENCE MERRY

I, Philip Laurence Merry, will say as follows:-

Section 1. Introduction

1. My name is Philip Laurence Merry and I was born on GRO-C 1949. I live at GRO-C Warwickshire, GRO-C. I am retired and married to Jennifer Margaret Merry and we have two sons, Matthew James Merry (date of birth GRO-C 1974) and Simon Philip Merry (date of birth GRO-C 1977). My wife and my two sons have also provided witness statements for the Public Inquiry.

2. I make this statement as an affected person in relation to my wife who was infected with Hepatitis C and my sons, Matthew and Simon, both of whom have been infected with HIV, Hepatitis B and Hepatitis C as a result of receiving contaminated blood products.

3. **This witness statement has been prepared without the benefit of access to Jennifer's, Matthew's or Simon's full medical records.**

Section 2. How Affected

Jennifer

4. My wife has a very mild deficiency of Factor VIII which was noted to be 13 percent just before her gall bladder operation which took place in November 1979. The only time she ever received Factor VIII was during this operation which took place at Coventry and Warwick Hospital. The consultant who carried out her operation was Mr Waterworth and her Consultant Haematologist was Dr Strevens.

5. At no time was my wife advised that there was a risk of receiving Factor VIII.

6. My wife was infected with Non-A non B (NANB) Hepatitis as a result of receiving the contaminated Factor VIII in 1979.

7. My wife became very ill with jaundice at the beginning of 1980. She firstly went to see her GP and then went to see Dr Strevens who told her that she had been infected with NANB. He even sent her to a tropical diseases doctor despite confirming that she had probably been infected via the contaminated Factor VIII. There was absolutely no possibility that she could have been infected in any other way.

8. She was not given sufficient information to allow her to understand or manage NANB. She was also given no information regarding the risks of transmission. She was led to believe that NANB was basically nothing to worry about. She therefore did not really think much about it at the time and must have dismissed it from her mind. She certainly had not been told that NANB could become a problem in the future.

9. In 1998 she gave her first and only blood donation and following this she received a letter stating that she could not give blood because she had Hepatitis C. She then immediately went to see Dr Strevens at Coventry and Warwick Hospital and he carried out some further blood tests and told her that she had been infected with Hepatitis C but that her body had now cleared it naturally.

10. Dr Strevens said that he would monitor her going forward but that never happened.

11. She was very shocked as she had no idea that she had been infected with Hepatitis C. However, on being given the shock Hepatitis C diagnosis she immediately recalled her 1980 NANB diagnosis, which she had completely dismissed from her mind because she was led to believe, by Dr Strevens, that this was nothing to worry about. However, she was acutely aware of the severity of Hepatitis C and the ramifications of what being infected with this virus meant.

12. Worryingly I had been giving blood on a regular basis long before we were married and continued to do so throughout our marriage. Therefore I could have unwittingly put numerous people at risk of contracting Hepatitis C due to the medical professionals failing to correctly and fully advise my wife about her infection at every juncture.

Matthew

13. Matthew has severe Haemophilia A and received blood products from 1978 which comprised of Armour and NHS. Matthew required regular treatments with such products. **Exhibit WITN0724002** is an extract from Matthew's medical records confirming the batch numbers of the treatment he received between 1978 and 1984. These extracts above differ in the number of treatments he received according to the records we kept; our records show more treatments than the above **Exhibit WITN0724002**.

14. Matthew was treated at Coventry and Warwick Hospital.

15. When Matthew was very young his consultant was Dr Shinton and as he became older his main consultant was Dr Strevens.

16. Neither my wife nor I were given any advice regarding the risk of Matthew receiving Factor VIII when he was young. As far as I am aware, when Matthew was old enough to manage his own affairs, he received no advice regarding the risks of receiving Factor VIII.

17. Matthew was infected with HIV, Hepatitis B and Hepatitis C as a result of receiving contaminated Factor VIII.

18. I recall that my wife had a meeting on 8th April 1982 with Dr Vinaygmoorthy at the Coventry and Warwick Hospital. He mentioned something about a form of Hepatitis to her.

19. He gave my wife some brief advice about washing her hands after clearing up blood spillages and putting needles into a sharps box. She was already being extremely careful and there was nothing he told her that she was not already doing.

20. **Exhibit WITN0724002** refers to paragraphs 18 and 19 above and is an extract from my wife's records which she kept in exercise books. Matthew had his bloods taken at the time my wife thought that it was because Dr Vinaygmoorthy said that his brother Simon was showing symptoms of a Hepatitis virus.

21. In relation to Hepatitis B, as far as I can recall no information was provided to our family in relation to this diagnosis which was made on 14th April 1983. **Exhibit WITN0724003** refers. No information or advice was imparted to us by the medical professionals.

22. In relation to HIV, I was standing at Rugby Railway station sometime in 1985 when a mother of a Haemophiliac boy who was also treated at the same hospital as our boys, came up to my wife and I and asked us if we had received a particular letter from the hospital. Jennifer and I told her that we had not received this letter. The mother then said "*In that case your boys are HIV positive*". This was not said with any malice, she was as concerned for our boys as she was for her son and was totally unaware that we knew nothing of our sons being tested for HIV. To this day Jennifer and I can't remember why we were at Rugby train station. Our world fell apart that day, we just couldn't take in this appalling news, being HIV would as we thought then bring about the death of our much loved boys, both Matthew and Simon had been given a death sentence.

23. Shortly after this horrific chance meeting, we were called into the hospital to see Dr Strevens and I remember little from this meeting, but I do know HIV wasn't mentioned as such and I can recall that a senior laboratory person called Mr Lavendon was also present. After this meeting Mr Lavendon came out into the corridor with us and said "*you didn't ask then*" and I assumed that too mean, it was up to us to ask if the boys were HIV positive. Still in total shock we could hardly speak let alone ask about our son's status. The hospital had no idea that the HIV bombshell had already been imparted to us by a parent of another Haemophiliac boy on the platform of

Rugby train station. The doctors at the hospital did not at any time seek our permission to perform an HIV test on the boys, if they had asked us for our permission it would have been granted and the truly shocking way we were informed would have been avoided.

24. At no point can I remember any of the medical consultants providing us with sufficient information to allow us to understand and manage the HIV virus. They provided no information on the risks of transmission. My wife had always been very careful with any blood spillages, syringes and needles and this was from the start of her taking on home treatment for the boys in 1982 which is confirmed in **Exhibit WITN0724003**. The consultants provided no follow up care in counselling or support to families like us, who had just received life changing news.

25. In relation to Hepatitis C I believe that Dr Strevens advised Matthew that he had Hepatitis C in 1991/1992, and I know that my wife was present as was Simon at this meeting. It was at this clinic meeting that Simon was informed that he didn't have Hepatitis C. This would have been a clinic appointment for both boys and I believe the last one they both attended together; Matthew would have been coming up for eighteen if it was 1992 so it was appropriate that he should begin to manage his own affairs.

Simon

26. Simon has severe Haemophilia A and received Factor VIII from 1979. **Exhibit WITN0724004** is an extract taken from a Preliminary Medico Legal Report, listing some of the blood plasma and batch numbers which Simon received. This extract differs with the amount of plasma given from the lists of treatment which my wife recorded at the time.

27. Simon was treated at Coventry and Warwick Hospital and his consultant was Dr Strevens.

28. **Exhibit** WITN0724002 also refers to the type of Hepatitis which Dr Vinaygmoorthy discussed with my wife on 08.04.82, but the type was not known until 1990/1991 after receiving and reading the Preliminary Medico Legal Report of which this exhibit also formed part of. Hepatitis B actually surfaced on the 08.04.82 to which **Exhibit** WITN0724002 refers although we were not aware of the actual diagnosis of Hepatitis B until 1990/1991 after receiving the Preliminary Medico Legal Report. Shortly after the meeting on 08.04.82, my wife telephoned the hospital to speak to a doctor (whose name we cannot recall) to ask about the risks of transmission because Simon was attending friend's houses in respect of birthday parties. However, this doctor assured my wife that she had nothing to worry about.

29. In relation to HIV, I repeat what I said in relation to Matthew at paragraphs 22, 23 and 24 above. However, I refer to **Exhibit** WITN0724003 in relation to Simon's home treatment.

30. In relation to Hepatitis C, Dr Strevens initially advised Simon that he did not have Hepatitis C and I refer to paragraph 25 above.

31. By 1996 Simon was attending hospital appointments without my wife. During a routine consultation regarding his HIV on 29th January 1996, Dr Strevens advised Simon that he was Hepatitis C positive. It was towards the end of the consultation and he just made a flippant remark as he was discussing Simon's HIV, which was "*and of course you have Hepatitis C*".

32. I remember Simon coming home from this appointment and being utterly distraught. We must have heard him park his car in the driveway because we both went into the hallway and opened the front door to see what was going on; he came indoors and started shouting at my wife because he thought that she already knew about his Hepatitis C diagnosis and had not told him. He was very upset and my wife finally managed to calm him down and told him that she did not know and that she had been told that he did

not have Hepatitis C. He didn't appreciate the severity of what Hepatitis C was, but was very upset.

33. My wife then telephoned the hospital to make an urgent appointment with Dr Strevens to discuss what had happened at Simon's consultation. We both went to see Dr Strevens the following Friday. Dr Strevens told us that when he initially tested both of my sons, Matthew had tested positive and Simon negative. Dr Strevens told us that he had not believed this test result so had had Simon's blood re-tested; the result of which was positive this time. Dr Strevens advised us that he realised Simon had not been aware of his Hepatitis C diagnosis as soon as he saw the shocked look on his face. He apologised for not telling us for a period of about 5 years. However, he did not provide us with any advice to allow us to manage or understand Simon's Hepatitis C.

Section 3. Other Infections

Jennifer

34. My wife received a letter in February 2009 advising that she had not been put at risk of vCJD.

Matthew

35. I am unsure as to whether Matthew has been put at risk of vCJD.

Simon

36. Simon was put at risk of vCJD. **Exhibit WITN0724005** is a letter dated 2nd October 2008 from Dr I B Draper to "*Dear Colleague*" which states "*Many thanks for seeing Simon who is 31 years of age and HIV positive, he has a*

history of Haemophilia A (Factor VIII deficiency), hepatitis C and is at risk of Variant Creutzfeldt-Jakob disease".

Section 4. Consent

Jennifer

37. I do not believe that my wife was tested for any viruses without her knowledge or consent. I do not believe that she was treated or used for the purposes of research without her knowledge or consent.

Matthew

38. We were aware that Matthew did have bloods taken when he was younger but we were never told what they were for, we just thought they were for monitoring his general health. It was only after the HIV diagnosis and as Matthew got older that we were told that some of the tests were for CD4 counts. As far as I am aware Matthew was not treated or used for the purposes of research without our family's knowledge or consent.

Simon

39. I repeat everything I said in respect of Matthew in paragraph 38 above. We did know Simon had been tested for Hepatitis, but not for which type to which **Exhibit WITN0724002** also refers. However, the test for HTLVIII was certainly done without our family's knowledge or consent. **Exhibit**

WITN0724006 contains some extracts in relation to tests undertaken in respect of Simon.

40. Simon strongly believes that both he and Matthew were used for the purposes of research. He postulates that being young severe Haemophiliac patients presented medical professionals with the "*perfect ready made research group*".

Section 5. Impact

Jennifer

41. I recall that Jennifer was very poorly shortly after her gall bladder operation in November 1979 and I believe that this was a result of her infection with NANB. I recall that she was not able to eat anything and that she was constantly nauseous and throwing up. I remember that she had to catch two buses to get to the hospital for her check ups because she was too ill too drive.

42. Although she was advised that she had contracted NANB in 1980 she was led to believe that this was not serious and that it would not cause her any problems in the future.

43. Therefore, it came as a huge shock when she was diagnosed with Hepatitis C in 1998. However, on the very same day, she also found out that her body had naturally cleared the virus. This was by anyone's definition an odd set of facts for my wife to process.

Matthew and Simon

44. What happened to my two sons was the worst thing that any family could go through. The impact on our family was, and is, almost indescribable. We chose not to tell our sons about their HIV infections until they reached the age of circa 12 years; this was so they could enjoy a little more time just being children. Those two conversations, which took place in our back room, where one of the hardest conversations I have even been involved in. It was so heart breaking watching my sons processing the moment when all their hopes and dreams for the future had been cruelly stolen from them.

45. I was at work so I missed the day-to-day caring for our boys. However, I did take the boys to hospital in the evenings when they needed treatments, before my wife did home treatment and also took holidays from work when we had appointments to see the doctors. I used to work in an office at Rolls Royce and my colleagues knew that my boys had Haemophilia. However, I never confided in anyone about the fact that they also had HIV.

46. I tried to keep life as normal as possible for my boys given the horrendous facts that they were coming to understand. However, not being able to tell people due to the risk of stigma took its toll. I struggled to cope with this strain and extra stress.

47. Jennifer would frequently become frustrated with me because I would keep things close to my heart. Jennifer wanted to discuss things and I was unable to support her in this way.

48. I always worried about my boys and I kept thinking that they would not manage in various difficult circumstances. This worry never left me.

49. I took things day-by-day and tried to keep things normal for our lovely boys.

50. Life has been difficult in the respect that you cannot just live a normal family life. Everything had to be dealt with with meticulous planning.

51. I have never really spoken about my son's infections with the community. However, I am now thinking that it may be better to tell people about our story when I meet them.

52. My mother died when I was 15 and my father remarried soon after, I never told my father, who passed away three years ago, or my two brothers about my son's status. Matthew informed us that he was appearing on the BBC news going public about being HIV positive. We knew then that my brothers had to know as it would be too shocking for them to find out through the media. So Jennifer e-mailed my brothers two days before the news program was broadcasted. My brothers were and are fine about my sons' conditions.

53. **Exhibit WITN0724007** is a psychiatric report of Bryan Lask, Consultant Psychiatrist, dated 18th May 1990 in respect of Matthew which states "*He tries not to think about the future and when he does feel upset he tries to distract himself….he would like to have girlfriends but knows that he will never be able to have children……his main concern is that he does not know what will happen to him….my impression of Matthew is that he has a strong psychological defence system which protects him from the true reality of his situation. This defence system is easily penetrated at which point he becomes clearly distressed…..However, it is clear that infection with the HIV virus has had a major impact on his life, and in particular on his emotional state. It is very likely in the next few years, even if he does not develop Aids, he will suffer major emotional difficulties. He will have to adjust to the probability of a far shorter than normal life, and a period of chronic ill-health. In addition it will be difficult for him to make satisfactory and lasting relationships with people of the opposite sex, because of the very real danger of cross-infection. He is already worried about this and distressed at the fact*

that he will not be able to have children. It is much to his parents' credit that his coping so well at present".

54. Matthew kept the news of his diagnosis to himself. He did not share this with any of his friends. GRO-C he just lived for the moment. It was expected that he would go to university, all things being equal, but he only scraped through his A-Levels.

55. Matthew ended up at Leamington Spa College and unfortunately, but totally understandably, wasted another 2 years of his life there. Then, Matthew realised that his friends were all doing well and he wasn't so he decided to move from GRO-C to Birmingham and turn his life around. Matthew shared a house with his school friends who had gone to University in Birmingham. He then developed a more positive attitude and I was and am so proud of how he managed to get his head around the most horrific diagnoses and consequential effects in such a positive way.

55A Simon had passed his 12 plus exams and was the only boy in his year to achieve this. It was hoped that he would go to university but naturally following the devastating news that he was infected with HIV and knowing that he may die from this infection, he felt condemned. His A-level results were awful but in his efforts to achieve something in whatever life he had, he managed to get into Plymouth University. He started an electrical engineering degree course but dropped out after only half a year. Simon could not manage to apply himself with any effectiveness to his studies. Such was the horror of the thoughts in his head. He managed to get on a computer course which helped him to gain some positions of work and gradually he restored some confidence in himself.

56. My wife used to regularly attend Coventry and Warwickshire Hospital to collect home treatment for my sons. In 1985 and shortly after I had found out that both my sons had been infected with HIV, my wife recalls that one of the laboratory personnel offered her Armour plasma which my wife

refused to accept and his reply was "*well they are infected*" meaning our sons. **Exhibit WITN0724007** refers. My wife still refused it and came away with NHS plasma. On another occasion my wife recalls Mr Lavendon saying to an Armour representative, whilst gesturing in her direction "*Oh there's one of our mother's*". The representative then had the audacity to sit down next to my wife and started to tell her that none of this was his company's fault. This was deeply upsetting for my wife and it made her so angry.

57. **Exhibit WITN0724008** is a psychiatric report of Bryan Lask, Consultant Psychiatrist, dated 18th May 1990, in respect of Simon which states "*I found Simon to be a very pleasant boy who spoke openly about himself. He fully understands that he is HIV positive and that he was infected from Factor VIII. He knows that he will never be able to have children, and that he may contract Aids, for which there is no cure and from which he might die. He did not know what the chances were of developing Aids, or of dying. He tells me that he does not like to think about his situation as it upsets him when he does……It is very likely that in the next few years he will experience more psychological distress as the full implications of his illness impinge upon him. It is very much to the credit of his parents that he is coping so well at present*".

Section 6. Treatment/care/support

Jennifer

58. As far as I am aware my wife never suffered any obstacles in relation to accessing any medical or dental treatment.

59. She was never offered any counselling or psychological support either as a result of her own diagnosis or in relation to our son's diagnoses.

Matthew

60. GRO-C

61. GRO-C

62. Simon recalls seeing a sign on Matthew's hospital door GRO-C GRO-C which said "*Risk of Infection*".

63. Matthew was never offered any counselling or psychological support.

Myself

64. I was never offered any counselling or psychological support.

Simon

65. When Simon was aged about 14, he was admitted to hospital following a bad bleed in his kidneys. He was placed in an isolation room which was out of the ordinary.

66. **Exhibit WITN0724009** is a letter dated 16th January 1995 from Iain Barker, Laboratory Manager to Dr D Galliford which states "*I know you are aware of this patient's high risk status. When requesting any tests from the Pathology Laboratory on him please could you attach one of the enclosed biohazard stickers on the top left hand corner of the request form? This will alert pathology staff without communicating to anybody else the high risk nature of this patient*".

67. During Simon's IVF they told him that being HIV positive was fine but because he used to have Hepatitis C, despite the fact that his body had already cleared this naturally, their embryo had to be stored in a separate incubator to all the other embryos. This was so that it could be checked and lifted in and out of its incubator, which did not foster the best developmental conditions and thus reducing the chance of a successful result.

68. Simon was never offered any counselling or psychological support.

Section 7. Financial Assistance

Jennifer and Myself

69. We have never received a penny from the Skipton Fund.

Matthew and Simon

70. From about 1990 both boys received £15 per week from the Macfarlane Trust (MFT). They also received a winter fuel payment of £440 per annum.

71. I believe that the MFT also provided about £500 in respect of each boy in or around 1991 so that we could go on holiday as a family to Bacton in Norfolk. They also funded a further £250 in respect of the same holiday.

72. The MFT refused our applications for grants for things such as bedding because my salary was considered to be sufficient. We were therefore not entitled to a number of grants or other payments on the same basis.

73. I found the application procedure for the MFT relatively straightforward but then the usual outcome was that we were refused any help or support.

74. I found the MFT fit for purpose up to around 1995 and we were grateful for the scraps of support that came our way. We were knocked back on so many occasions so when we finally got something from them we were extremely grateful. I suppose this is one way to keep those people already suffering *"happy"*.

75. After Matthew's car accident, his car was a write off and because he was on the Motability Scheme he asked the MFT for a £1,000 for a new car and they granted this.

76. Once Simon was old enough to deal with his own affairs he took over the management in relation to matters pertaining to the MFT and he discusses this in his witness statement.

77. Simon did not receive a penny from the Skipton Fund because they successfully postulated that he his body had naturally cleared the Hepatitis C virus. This seems entirely unfair and ludicrous.

78. Each boy received the ex-gratia payment sums of £20,000 on 9th February 1990.

79. We were involved in the previous HIV litigation of 1991 which necessitated that we signed a waiver. Each boy received £21,500 on an ex-gratia basis and this was held in Trust for them by Queens Bench Master Turner. My boys only received the smaller sum because they were expected to die before adulthood. We had to sign our rights away in order to receive this derisory sum and then up popped Hepatitis C shortly afterwards.

Section 8. Other Issues

80. I want justice. Due to the horrific stigma attached to HIV we have been unable to talk about this tragedy until relatively recently. The impact and ramifications it has had upon us as a family was, and is, indescribable. You should be able to protect your children but we were unable to do this. We were treated abominably and shown no compassion or empathy. We were expected to get on with it and basically man up. It was like because our sons had Haemophilia they were somehow expected to have to deal with these horrific infections as a matter of course and to do so quietly with the minimum of disruption to society. I was in a position where I could have lost my wife to Hepatitis C and both my sons to AIDS.

81. If any compensation arises in the future I would like my sons, together with everyone else, to receive the same amount of compensation. The emotional journey was and is the same for everyone, whether they are young, old or have children. This has been no ordinary life.

Anonymity

82. I do not wish to apply for anonymity and I would like to give oral evidence to the Inquiry.

Statement of Truth

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

Signed... GRO-C ....

Dated... 30 April 2019 ....