Witness Name: Peter Vaughan
Statement No.: WITN5408001
Exhibits: **WITN5408002-3**
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF PETER VAUGHAN

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 19 August 2021.

I, Peter Vaughan, will say as follows: -

Section 1. Introduction

1. My name is Peter Vaughan. My date of birth is GRO-C 1957 and my address is known to the Inquiry. I am a retired engineer and live with my wife.

2. I intend to speak about my infection with Hepatitis C ("HCV"), as well as my late brother, Nigel's infection with HCV and HIV. In particular, the nature of mine and Nigel's illnesses, how the illnesses affected us, the treatment received, and the impact it had on myself, Nigel, and our lives.

3. I can confirm that I am not legally represented and that the anonymity process has been explained to me by the inquiry investigator and I am happy for my story to be in the public domain. I will make this statement

without access to medical records and dates should therefore be taken as approximate although I will try to tie them to significant events in my life.

Section 2. How Infected

4. Nigel and I inherited haemophilia from my mothers' side of the family (my mother's father was a haemophiliac). Both Nigel and I were diagnosed with mild haemophilia as children - Nigel would bleed more than me, but I would bruise more than Nigel.

5. When we were children in the 1960's, we did not have that many trips to the Children's hospital in Birmingham to treat bleeds. As young children, we also did not have dental treatment in the hospital just at the local dentist surgery. We would have fillings without injections, and I recall that we would bleed for a long time when we had teeth out.

6. I was not treated with any blood products until I was in my teens and underwent minor operations. I remember having my first lot of cryoprecipitate when I was around 12 for the removal of two teeth at the Children's Hospital Birmingham where I was admitted for 10 days. Later, a second stay at the age of 14 for a further teeth removal operation led to a stay of five days.

7. I was transferred to the Queen Elizabeth Hospital Birmingham for treatment when I was around 15 or 16 years old.

8. In 1984, I moved to Worcestershire. Any dental procedures from this time until the mid 1990's I had done at Worcester Royal Infirmary, however anything more complex, I was treated in Birmingham.

9. During 1984 I had an accident at our cottage when I was replacing an upstairs window. I turned my ankle coming downstairs, and because I didn't rest, the joint bleed worsened to the point that I had to go to the Queen

Elizabeth Hospital Birmingham. I was given Factor VIII injections twice a day for approximately one week, returning to the hospital every day

10. In 1986, I had an eye operation at Birmingham Eye Hospital to treat exotropia strabismus in my left eye. During my weeks stay in the hospital support for my Haemophilia was provided by the Queen Elizabeth Hospital sending staff over to administer Factor VIII twice a day and I recall a particularly high dose of Factor VIII prior to the operation. After returning to Worcester, I attended Ronkswood Hospital in Worcester twice a day for a haematologist to continue my Factor VIII treatment and this carried on for approximately one week. All factor VIII was provided by the Queen Elizabeth Hospital which I bought home with me and took to Ronkswood Hospital.

11. In 1992 / 1993, I received a letter from the Queen Elizabeth Hospital Birmingham to say I was showing antibodies for HCV. I remember feeling very relaxed and was not worried about the diagnosis. I was fit and well and I knew I had not made much use over the years of cryoprecipitate or Factor VIII. I didn't know much about HCV and the diagnosis was in 'matter of fact' terms and did not trigger any alarm bells with me. However, as we didn't know too much about it and my wife was worried, I contacted the haematology department in Worcester Royal Infirmary and subsequently saw Consultant Haematologist Dr GRO-D Dr GRO-D informed me that there was no treatment available for HCV, and to go home and not worry about it. Very little else was said about the infection.

12. A few months later, I received a follow-up letter from Dr Johnathan Wilde at the Queen Elizabeth Hospital Birmingham, asking me why I hadn't been in touch regarding my HCV diagnosis. I was a bit shocked by this bearing in mind what I had been told earlier by Dr GRO-D I went to see Dr Wilde, who informed me that HCV was something to be worried about, and gave me the low down about what it was. He told me that the hospital had a trial going on for treatment for the infection and asked me to join.

13. No advice was given to my wife and I on the risks of infection and cross-contamination by either of the doctors and I don't remember any leaflets being handed to us. My wife did become very worried about the implications and carried out research into the subject. She was later tested for HCV when we saw Dr Wilde, at his suggestion, at the Queen Elizabeth Hospital Birmingham. Fortunately, that was negative.

14. I have no memory of any risk of HCV or HIV being mentioned when I was given blood products, nor was I given any options in relation to having treatment. At the time there was no alternative in any case.

15. In 2005/2006, the operation I had on my eye in 1986 was repeated at Worcestershire Royal Hospital. Unlike 1986, this only involved an overnight stay in hospital, and I received Factor VIII prior to, and for a few days following surgery. From memory I believe the Factor VIII was provided by The Queen Elizabeth Hospital in Birmingham.

16. Nigel mostly had accidental incidences as well as a few major injuries which required treatment. I recall Nigel received cryoprecipitate following a camping trip where he trapped his thumb in a camping stool. This was in the 1960s, with the camping accident around 1968. Medics at the Queen Elizabeth Hospital Birmingham put a Tubigrip dressing on his thumb, however as they used a dry gauze to dress his wound, his nail came off when the dressing was removed at home a week later and it started bleeding quite severely. Nigel received a large amount of Cryoprecipitate over the following days with the injury causing blood loss of 1-2 pints.

17. I am aware that in 2000, my parents got in touch with a local MP, Mike O'Brien regarding the way Nigel had been treated, presumably by the NHS but, unfortunately, I am unable to expand on this. By this time Nigel was living in Coventry and with us living in Worcester we did not see a great deal of each other. My parents were very private and often kept the details of what was happening with Nigel from me. I think there was a sense of

guilt on their part about how his life had turned out and, as I will mention later it was during this year that he was diagnosed with HIV.

18. I believe Nigel would have had his letter of diagnosis of HCV at the same time as me, as we started the trial at the same time.

19. I don't remember anything around consent or warnings given to Nigel as our conversations were limited. I know that Dr Wilde advised him to stop drinking. However, Nigel ignored this.

20. Nigel never married, so there was not an issue regarding having his wife tested for HCV as well.

21. I was not aware that Nigel was HIV positive. We had suspicions but nobody said anything. However, his medical record shows he was HIV positive in 2000. **(See Exhibit WITN5408002)**

Section 3. Other Infections

22. Apart from HCV, I have I do not believe that I have received any other infections from contaminated blood products.

23. I do not believe that Nigel received any infections other than HCV and HIV from contaminated blood products.

24. I did receive a large letter some years back from the Government in relation to vJCD. I recall it was extensive, maybe 10 pages or so and dealt with the fact there was no test for the disease. It sticks in my mind about dental work as I recall having my own set of instruments at the dental hospital and this was because you could not remove contamination with vCJD through normal sterilisation procedures.

25. I thought when I received it that it was the authorities covering their backs. There were no tests and no known cure so what was the point in telling you about it – it was just something else to worry about.

Section 4. Consent

26. I was never aware that my blood was being tested for HCV prior to my diagnosis. It was not until the early 1990s that I was tested for HIV. I remember being told that I was tested and that I was negative. Again, I was not aware that the blood I supplied was to be used for that purpose.

27. I did not receive treatment and was not tested for the purposes of research without my consent as far as I am aware

28. I am not aware as to whether Nigel was tested or treated without his knowledge or consent.

Section 5. Impact

29. Prior to diagnosis and taking part in the clinical trial and receiving treatment, I did not experience any mental or physical effects or symptoms of being infected with HCV. I did, however, suffer from something like the flu but more severe, in 1987, and again in 2013. Both times I went to my doctors and had blood tests, and was told that my white blood cell count had been affected. The doctors put it down to 'a flu virus', however, it had to be something really serious to stop me from getting out of bed as it did and I believe there is some connection between these episodes and the HCV infection.

30. The clinical trial was undertaken at the liver department of the Queen Elizabeth Hospital Birmingham and required me to first have a liver biopsy prior to commencing the trial. The biopsy was extremely painful, and I had to lie still for 8 hours following the procedure. On a scale of 1-13, my result

of the biopsy was 5. I did not receive a second biopsy following the completion of the trial.

31. The trial comprised of taking oral tablets twice a day (Ribavirin) as well as injections (Interferon) which I administered myself three times a week for 12 months. This was between April 1997 and April 1998. The course successfully treated the infection.

32. The treatment affected me greatly. Because I was self-employed, I had no choice but to continue working during the 12 months of the trial as this was my only source of income to pay our mortgage and household bills. The side effects were awful - I felt so ill, think of a bad hangover and double it, with lots of flu-like symptoms. I suffered greatly with fatigue, and it is true to say that I have never returned to the level of well-being that I enjoyed before the treatment - it's almost as if the treatment was as worse than the infection itself. I wouldn't mind so much if I had symptoms before or had suffered in some way but I didn't. During the treatment period my wife and I tried to carry on as normal as possible including going on holiday. Unfortunately, I was always too fatigued to get out and walk, and my wife spent most of the holiday on her own most of the time due to this. Further side effects I experienced were ulcers in my mouth, which made eating painful and scabs on my scalp, and generally feeling run down. However, these all disappeared when treatment finished. During treatment, I was regularly monitored attending the Queen Elizabeth Liver Clinic monthly to have blood tests and collect my prescription for Ribavirin and Interferon.

33. Following completion of the treatment, I didn't tend to notice any further major symptoms - although I worked for myself, and I could not afford to notice things. I now have joint problems and think I am starting to suffer from arthritis. Following my eye operation in 1986 I started to develop Psoriasis which although it was painful at times, only affected my knees and elbows. Following my HCV treatment, the Psoriasis has become much worse affecting approximately 20-25% of my body area. I am a firm believer that this is to do with the HCV infection. In hindsight, the fatigue particularly

never really went away. It was just that my work ethic did not let me see it there.

34. I did not receive any further follow-up after treatment apart from a PCR test after six months for confirmation. All I do now is visit the Queen Elizabeth Haemophilia Unit when I have problems or need factor VIII for dental treatment (also at the Queen Elizabeth Hospital). There was no follow-up in relation to my liver. I was elated when I successfully completed the course as I thought I can get on with my life but little did I know.

35. I did not need any medication after treatment. I am a glass-half-full type of person and as I am self-employed, I couldn't afford not to be. At one point though I got addicted to co-codamol which had been prescribed due to the pains I experienced during treatment and after treatment ended, I carried on taking co-codamol pretty well every day just to feel OK. In the early 2000s I realised I had a problem. I thought to myself I need to stop - I knew I had gotten to the stage where I was taking too many.

36. My wife was badly affected by my HCV diagnosis, it was a very worrying and stressful time for us both. GRO-C

GRO-C

37. GRO-C

38. We experienced a lot of anxiety and tension during this period - there was no one there to advise you and say, "Peter's alright, that's how he should be reacting to the interferon". Due to the stress our whole life was turned upside down. Our married life and relationship became strained. Luckily, we were able to work together and we turned things around. I don't think

people realise the enormity of the burden HCV treatment can place on a couple. We drew on that new-found strength again following my wife's GRO-C and we've been alright since.

39. As we are a small family and do not have any children, no one else was really affected due to my HCV infection.

40. Now I have finished work I do feel a lot better both physically and mentally, and I have to be reminded to rest now. I am not under pressure from work, and I feel better now than I have done for years.

41. Work-wise, as I was self-employed, the HCV infection and stigma attached didn't affect me much as being self-employed and working from home most of the time I didn't have to tell people. The year when I had treatment I lost around half of my income, but between my wife and I, we managed to get by. Fortunately, the infection did not affect our mortgage, however, it did cause difficulties trying to find a new mortgage in 2002 when we wanted to move house.

42. With regards to my business, I did lose a few clients who were upset with me not being able to meet deadlines due to my reduced working capacity during the twelve months of treatment. Fortunately, because there were not many people providing a similar service - or as competitively, I managed to retain most of my clients.

43. The infection has affected my income, and it was never the same after treatment. It is hard to quantify the losses however, I should have been ok to go on working until my mid to late 60s, possibly longer rather than stop working at 63. We are fortunate to have support from EIBSS.

44. When we moved in 2002, we had issues getting quotes for mortgages due to my HCV infection. We took on the house without insurance, and the costs were a lot higher as a result.

45. I will now deal with the impact of the HCV – and HIV on my brother Nigel. He suffered from depression, which was exacerbated by his HCV diagnosis. In 1980, on our father's birthday, Nigel tried to take his own life - I am not aware of any other incidences like that, and Nigel was never sectioned. I believe that it may have been an overdose of painkillers mixed with alcohol but again, this is second hand information. As I've mentioned previously, much was kept from me by my parents due to I suspect not wanting to worry me, coupled with a tinge of guilt on their part over allowing Nigel to have been given blood products during his life, albeit they did not know at the time of treatment what the future would hold. Finding out that he was HIV positive tipped Nigel over the edge - Nigel could not see a future and gave up.

46. When Nigel was first diagnosed, he was cutting down on the drink. However, mentally it got to him and as the mental impact grew, the drinking got worse. Nigel would go down to the pub every lunchtime. In turn, this affected my mother who would go and visit Nigel and he would be at the pub instead of at home, which upset her to the extent that eventually, my father stopped taking my mother there to prevent her from witnessing Nigel in the state he was. His behaviour did nothing GRO-C

47. Physically, the HCV also exacerbated Nigel's joint problems, and by 1997 / 98 Nigel was using a stick, then a frame, and then finally a chair, all in a short space of time.

48. We were both part of the same clinical trial for HCV treatment. Nigel had a liver biopsy slightly ahead of me, with his result being 7 on a scale of 1 to 13.

49. Nigel only lasted three months on the treatment and said he couldn't complete it due to the side effects. As Nigel's liver was worse, I presume the side effects were worse for him. As Nigel did not complete the 12 months treatment, I am unaware as to whether Nigel cleared the virus.

50. I know he didn't work much after the 1990s. My parents had a caravan in Burnham on Sea in the late 1990's and he went to live there. Nigel worked part time on the switchboard at Western Super Mare Hospital.

51. Nigel was a very matter-of-fact type of person, and my wife had a closer relationship with him than I did. She spoke to him more than I did. Nigel used to suffer from 'the blues' and could get really down, despite my wife trying to cheer him up on the phone. Nigel's answer was regretfully the bottle, which would in turn make him feel worse.

52. Nigel had unreliable friends, and my parents were not in the real world about what his lifestyle was like. My parents always believed that it was everyone else's fault for the way Nigel lived. – and died.

53. Following treatment, Nigel's health got worse, and he came back up to live in sheltered accommodation in Atherstone in 2000 / 2001. Nigel had a stroke during this period, however, despite medical advice his alcohol consumption did not stop.

54. My parents retired to Bromyard, Herefordshire in 2000. They continued to visit Nigel in Atherstone on a regular basis to help him out. My mother became ill with Rheumatoid Arthritis in 2001 and eventually, my father stopped taking her to see Nigel which caused acrimony but he thought he was doing the best thing for her and her health.

55. In the end, my wife and I were the only ones in contact with Nigel, and he came to visit us in 2002 in a wheelchair. Not long after that he had a second stroke and was found unconscious. Nigel was taken to hospital but never regained consciousness. My parents managed to get to the hospital as next of kin, and not long after that Nigel passed away.

56. Brian, Nigel's carer, who was with him for some time at Atherstone, would know a lot more than we do regarding Nigel's medical treatment. There were multiple occasions when Nigel had gone to the hospital and we

wouldn't know as my parents were trying to save us from all the worry - my wife was in hospital in March and April 2001, and they did not want to burden us with any more worry. I do not know what medication Nigel was on when he died.

57. I am not aware of any problems with the release of the body. The cause of death on Nigel's death certificate is a stroke and haemophilia – I suspect that my parents did not want HCV or HIV mentioned on the certificate and were able to persuade the certifying doctor to that effect. **(See Exhibit WITN5408003).** Nigel was cremated and as far as I know that was his wish.

58. Nigel's diagnosis greatly affected my parents who took care of him and financed him as Nigel could not hold down a job after diagnosis.

59. My parents bought Nigel a flat and a caravan and bought him cars when he was able to drive, and this had a massive financial impact on them.

60. Their generosity with Nigel did not change my relationship with either my parents or Nigel as I would rather have my health. I know that Nigel did not want my parents running his life, however, he could not live without their support - I think he felt that they treated him like a child during this period.

61. It was devastating for my parents to watch their two sons be diagnosed with HCV (and Nigel HIV), and watch Nigel go so quickly downhill.

62. **GRO-C**

63. **GRO-C** **GRO-C** My mother never got over Nigel's death and did not last long after Nigel passed, and sadly died in December 2004. I believe what happened to Nigel contributed to my mother's death. Possibly, she gave up on life because of all that had transpired.

64. My parents would not tell anyone about Nigel and my diagnosis. My father was a dispensing chemist and knew all about the stigma that was attached to HCV and HIV diagnoses.

65. Nigel's HCV and HIV status further caused a family rift. Our brother, David had young children and my parents discouraged Nigel spending time with their grandchildren as they were worried about the infection being passed on. Nigel was not generally at my parent's house at the same time as David and his children, and Nigel also wouldn't be invited to Christmas and birthday get togethers. This hurt Nigel deeply as he was very fond of the children and he was very sad about being excluded.

Section 6. Treatment/Care and Support

66. When I was initially diagnosed, dental staff at the Queen Elizabeth Hospital would treat me in full-blown PPE, gloves masks etc. Things have now become a bit more relaxed regarding treatment. I recall I also had instruments that were just for me when I underwent treatment. I believe this was to do with the risk of vCJD and the issue that the autoclaves did not get rid of BSE from instruments.

67. I was not offered any psychological support or counselling when I was diagnosed nor at any stage during treatment. Later on, the Queen Elizabeth Hospital Birmingham employed a social worker in a support capacity but I did not feel the need to see them. It was a bit too late and I had already got through the worst of it.

68. I do not remember Nigel being offered any psychological support following his diagnosis or during his failed treatment. In hindsight it is something that he may have found useful but whether he would have accepted the help I couldn't say.

Section 7. Financial Assistance

69. In 2004, someone contacted me regarding the Skipton Fund. I can't recall where the information came from.

70. I completed an application form without too much trouble and took it to the Queen Elizabeth Hospital Birmingham who sent it back to the Skipton Fund. I received a £20,000 lump sum payment, although I believe it took quite a while to come through.

71. I now get monthly support from EIBSS, around £1,600 a month which I consider a reasonable sum.

72. I applied regarding Nigel in 2011 when Skipton said they were going to pay out to bereaved estates. My father received payment as Nigel's next of kin. There was no problem with accessing this money, and Nick Fish was very helpful when I spoke to him.

73. I am grateful for the financial support I receive now. However, I could have done with it when I was undergoing treatment. As we no longer have a mortgage, the support I receive has allowed me to retire from work which has helped.

Section 8. Other Issues

74. For my part, I want to get to the bottom of who knew what and when. In the recent hearings, Ken Clarke has said exactly the same thing as what he said in the 1990s. It will be interesting to see what comes out of this Inquiry.

75. People who should accept responsibility are gone, and most of the people who should answer the main questions are not here anymore either. It is all a long time ago but still has a major impact on so many lives.

76. It will be beneficial for some of the infected individuals to know what happened and why. However, for some of the families, things will not or cannot ever be put right. Despite this, I do hope this Inquiry will bring some sort of closure to all those that have been infected or affected.

77. I should now mention briefly that I have subsequently made a claim through the English Infected Blood Support Scheme in relation to my brother Nigel's HIV infection and they have accepted the validity of that claim and made payment of £43,500 as a lump sum to his estate. Whilst it won't bring my brother back, I am happy to receive my share of the this via my father's estate in recognition of what happened to Nigel, through circumstances that were in no way any fault of his own.

Statement of Truth

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

GRO-C

Signed ____________________

Dated 4th February 2022.