Witness Name: Louise Nancy Veale
Statement No.: WITN5212001
Exhibits: Nil
Dated: 2.10.22.

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF LOUISE NANCY VEALE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 25 July 2022.

I, Louise Nancy Veale, will say as follows: -

Section 1. Introduction

1. My name is Louise Nancy Veale (nee Fletcher). My date of birth is GRO-C GRO-C 1964, and my address is known to the Inquiry.

2. I used to assist my husband with the secretarial aspects of his building business, but now I can no longer do this because ill health means I have minimal use of my fingers.

3. I intend to speak about my infection with Hepatitis C ("HCV"). In particular, the nature of my illness, how it has affected me, the treatment I have received and its impact on my family and our lives together.

4. I confirm that I am not legally represented and am happy for the Inquiry Team to assist with my statement.

5. The Inquiry Investigator has explained the Inquiry's statement of approach and 'Right to Reply' procedure. I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.

Section 2. How Infected

6. As a baby, I was diagnosed with a condition requiring a stoma and a bag for urine as my kidneys were not working properly. At 16, I was informed that they would have to reverse this procedure because even though I had a bag, the urine was being redirected into my kidneys. One of my kidneys stopped working completely and the other was functioning at about 5% and 10 % capacity before the surgery.

7. I was informed that I would require regular dialysis while I await a kidney transplant. It was devastating news at the time. While going through dialysis, my veins kept collapsing and it became pertinent for me to have the operation.

8. On 13 November 1981, I was admitted to Southmead hospital in Bristol to have a kidney transplant operation, and my consultant surgeon was Dr Barry Pentlow. Before the transplant, the doctors carried out a tissue test to ensure that my blood was compatible with the kidney donor's.

9. It was a complex operation which lasted five and half hours even though the procedure usually required only three hours. I am not sure if I received a blood transfusion during the operation. Afterwards, I was transferred into the ICU for five days and kept in a barrier room where nobody could come and visit me.

10. I was very ill and cannot remember much of what was happening at that time. Nearly five weeks later, at the start of December, I was discharged from the hospital and life carried on as usual.

11. I had an operation as a child and other medical procedures, but none of them required a blood transfusion.

12. The renal team at Southmead Hospital continued to carry out annual check-ups following my kidney transplant. In 1992, I believe, while under the care of Dr Christopher Burton, the doctors informed me that my most recent blood test had come back positive and I had contracted HCV. I think I was given the information in a face-to-face meeting.

13. I was in shock, I was not due to go to the hospital for another 6 or 8 months so the blood test would have occurred at least four to six months before, and no one had informed me that my blood was being tested for HCV. Dr Burton said he would refer me to Dr Barry at Bristol Royal Infirmary.

14. At the end of my meeting with Dr Barry, he gave me literature to take away with some information about my diagnosis. There was a discussion about the possible effects on my kidney They also advised me to reduce my alcohol intake, but I decided to quit drinking alcohol altogether. I don't recall any verbal information about other precautions to take.

15. After reading the literature, I became concerned about my son or partner contracting HCV, so I asked Dr Barry if this was possible. Dr Barry advised that there was only a 1% chance of transmitting the infection to either of them, but he also advised me to inform my partner and to get them both tested for HCV. This was a very anxious period in my life when the two persons closest to me could have been put at risk unwittingly by me.

16. **GRO-C**

17. I had to have three liver biopsies, the results of which confirmed that I had scarring on my liver. The first time I had a liver biopsy was fine, but on the second occasion, it was painful at first because they had not used enough local anaesthetic. Once I told them, they remedied this. During the third liver biopsy, there were no lights in the hospital due to a power cut, so they had to use torches, but other than that, I found the biopsy procedure okay.

18. Following my diagnosis with HCV, my first thought was that HCV was like AIDS. My mum even referred to it as artificial AIDS. I had been on anti-rejection medications since my kidney transplant and would continue taking them for life. It meant that I had no immune system to speak of.

19. Dr Barry continued to monitor my health every six months, but my appointments with the renal team were more frequent.

20. I began to get jaundiced, and from time to time, my mum made comments about how I looked yellow. Otherwise, I was in good health. I even participated in the transplant Olympics six months after my kidney transplant.

21. I had also started to feel fatigued, but I had a son to look after, so whatever my feelings were, I had to set that aside. I often contracted urinary tract infections, but I put this down to my kidney issues.

22. Finally, in or around 2001, I was offered HCV treatment. I was informed that my HCV was active and getting worse and that it was necessary for me to receive treatment. I discuss the treatment I received and the impact on my health in further detail below.

23. I have never been an intravenous drug user. I have always had to have blood tests due to my kidney illness, and I find it comical to highlight because these would have flagged that up to medical professionals.

24. I cannot be certain about ever having a blood transfusion, and it is my belief that during my kidney operation, I must have received a contaminated tissue or kidney. It could have also been the case that I received a blood transfusion during the operation.

Section 3. Other Infections

25. I do not think I have received any infection other than HCV due to being given infected blood or blood products. I am not aware if my blood was tested for the presence of HIV and if it was, I was never made aware of that or the result. It seemed to me at the time information about what tests you had done was on a need-to-know basis.

26. I am not sure whether I received a blood transfusion. The HCV infection could also have been transmitted through the tissues or kidneys during my first kidney transplant surgery in 1981.

Section 4. Consent

27. I was not aware that my blood was being tested for HCV. Before my kidney transplant, no one ever informed me that the procedure carried a risk of contracting a blood borne virus. They seemed concerned about blood infections rather than viral. I do not know if they were even aware of the existence of HCV at the time.

28. I have volunteered to be a guinea pig on a couple of occasions. For example, I recall being informed that a gentle myelin washout treatment which was to get rid of an infection, had not been approved for people who have had kidney transplants. I volunteered for them to try this out

on me because my infections were so horrendous. This procedure has now been approved.

Section 5. Impact

29. One of the reasons my husband and I finally got married was because he was concerned that I was going to die soon. The diagnosis coupled with my kidney condition was like a death sentence hanging over me and I can't imagine the pressure that this put on my husband and family at the time.

30. Dr Barry offered me treatment with Alpha Interferon, and due to my kidney issues, I was informed that I could not have Ribavirin because it secretes through the kidney. Dr Barry and Dr Burton consulted together and decided on the treatment plan. Dr Barry also advised on some potential side effects of the treatment with Interferon.

31. When I went to the hospital to pick up my prescription for the treatment, the male nurse on duty insisted on giving me Ribavirin. I told him that I was not allowed to have Ribavirin because of my kidney issues, but he said Ribavirin was the sister medication to the Alpha Interferon and that I needed to have it so I took it as he was the medical professional. The Ribavirin dosage was measured according to my weight, so he gave me a lot of this.

32. I began taking the medication the next day. I had to inject the Alpha Interferon into my stomach. I was already on Erythropoietin (EPO) Iron for my kidneys which also had to be injected into my stomach. The Ribavirin was in tablet form.

33. Within three days of commencing the treatment, I felt seriously unwell. I contacted the Bristol Royal Infirmary because this felt more severe than the side effects I had been told to expect. I felt physically drained and

my body ached. The hospital staff dismissed my concerns and said this was just what to expect when on the medication. However, I insisted that I should be allowed to come in for a blood test, and the nurse agreed that I could do that.

34. It took me 45 minutes to get myself out from under the duvet and get dressed. A trip to the hospital, which would usually take 5 minutes, took about an hour, as I was too weak to drive and, in any case, it would have been dangerous, the state I was in.

35. At the hospital, I had a blood test and then returned home. As soon as I got in, my phone began ringing, and it was the hospital. They told me I had to return to the A & E department the next day.

36. I called my mum over and asked her if she would be able to drive me to the hospital as my husband was away at the time.

37. When we arrived at the hospital, I was immediately admitted onto the wards. I was so weak that on arrival, they asked if I required a wheelchair.

38. I was delirious at the time, so I do not remember this, but my mum recently informed me that Dr Barry came down to the wards when I was admitted and said, "you should not have had the Ribavirin. I did not prescribe it, but I signed the prescription; let's hope she gets better." She says he did not apologise, he just made those comments and walked away.

39. When I was admitted, my HB count was 3. However, a good HB count is usually between 11 and 15. The medication had utterly depleted me. I had to have blood transfusions for about a week to bring my levels back to normal. Dr Barry took responsibility for the mistake, but he did not apologise for it. I was so ill I feared for my life and it was a very worrying time.

40. Nobody told me to stop taking the Ribavirin, I did it of my own accord just because it had caused such a strong reaction within a short space of time.

41. I was angry after this incident. I am quite a strong-willed person, and I believe this is why I survived. I had to beg to have the blood test taken in the first place, yet they said if I had waited any longer to come into the hospital, I would have died.

42. After I came out of the hospital, I had to start a new round of treatment with Alpha Interferon which lasted for six months.

43. The treatment was awful, and it turned me into a vile person. I felt angry and aggressive all the time. I was starting fights with my husband and the neighbours. It was like there was a red haze in front of my eyes. On one occasion, I was so angry at my husband that I tried to get my rottweiler, who was very protective of me, to attack him. GRO-C GRO-C

44. I had undergone a total change in personality. I put everyone through hell. I experienced extreme mood swings, moving from crying to violence. It was horrible. My husband said he felt like locking me away in a room at one point and that it was like being with Freddy Krueger on the rampage.

45. At the end of the treatment, tests showed that I had cleared the HCV. However, three months later, further tests to confirm this indicated that my viral load was up again. Unfortunately, this meant I had not cleared the Hepatitis C.

46. I was devastated and felt so frustrated that I - and my family had suffered all this upset for nothing but I was informed that I would start a new round

of treatment almost immediately and it started within a week or so and was to last for 3 months.

47. The second course of treatment made me depressed. I locked myself in a room and sat there and cried. I cannot recall what I was upset about; it felt like I was upset about nothing. I lacked appetite and, as a result, lost weight, drastically, at one point weighing only 7.2 stones.

48. After the second round of treatment concluded, I was again informed that I had cleared the HCV, and this time the further tests confirmed that I remained clear.

49. I think the side effects of the first round of treatment were more severe as it had a massive impact on everyone around me. Both rounds of treatment were not nice to say the least, but I tried as best as possible to get on with it.

50. Not long after successfully clearing Hep C, I was informed that my kidneys were failing. My renal consultant at the time, Dr Udayaraj, confirmed this was probably due to the ribavirin treatment I had in the first round of treatment. However, the news was delivered in person by another doctor, Dr Dudley, I believe because of his manner of delivery which was very matter of fact. They explained that I was in end-stage kidney failure again, and I would have to go back on dialysis. This was now around 2007.

51. In the meantime, I lodged a complaint to the Bristol Foundation Health Trust about the first round of treatment. I recall stating that I was making the complaint because I did not want someone else to go through a similar experience. I did not want compensation. I believe it was negligent, someone should have checked, and Dr Barry should have read the prescription he signed.

52. I received a response, which was an apology letter and that the matter would be followed up, but I never heard anything back from the hospital regarding the complaint after that. I never saw that nurse again, and I do not know if he was reprimanded for his actions.

53. In 2007, I was devastated at having to go back on dialysis. From previously being on dialysis, I was aware that there were limited access sites on my body. I also could not have peritoneal dialysis because of all the scar tissue on my stomach resulting from all the operations I had had as a baby.

54. They were able to find an access point on my shoulder and used a graft to make this point. However, during this hospital visit to Southmead, I contracted MRSA and required a fistula in my other arm to cure that.

55. I remained on dialysis for another two years. In 2009, my mum and sister took tests to determine if they were compatible matches for a directed kidney donation. They were both a match, and my sister decided that she was happy to donate because she had four children and didn't want any further kids.

56. The operation was successful. However, this kidney has only been working at about 30% since the operation in 2009. Currently, I am in end-stage kidney failure. From being ill for so long, I know the signs and can understand the meaning behind some of my test results. From recent tests, my creatinine levels are rising, and my phosphate levels are high.

57. Up until the HCV treatment, my former kidney had been working at about 60-70%, which is very good. It was a great match, and I had it from 1981 up until 2009. It was destroyed through no fault of its own – or mine.

58. I have been on various medications and developed several side effects over the years. The anti-rejection medicine I was prescribed after the second kidney operation, Tacrolimus, has caused me to develop several

small skin cancers which have had to be removed. At one point, I attended every four weeks to have another one removed. As a result of the scarring, I have lost a finger. I have had up to 11 cancerous removals done in one go, plus other removals aside from that. I have recently had a new growth removed from my upper cheek just under my eye. The location made it difficult as they needed to cut quite deep but it was successful and is healing up well.

59. I was on Azathioprine, an anti-rejection medication which stopped after my second kidney operation. It causes bone weakness and promotes arthritis, and Sirolimus which is responsible for my current diagnosis with diabetes, yet another illness that requires medication

60. Additionally, I have arthritis now, but my doctors said this is a result of the anti-rejection medications I have been taking since my transplant in 1981. I have never slept that well, and I still have that side effect. Either I sleep too heavily, or I have no sleep at all. I also suffer from short-term memory loss though I am not sure if this started before or after the HCV treatment.

61. Between 2007 and 2009, while I was on dialysis, I developed septicaemia and MRSA, and on several occasions, I had to have a kidney scrub to treat the MRSA.

62. I noticed that I used to develop complications whenever I attended the satellite hospital unit at South Bristol. The graft I was given to assist with the dialysis developed a lump where they had injected the needle into it. there was one occasion where I complained of pain to the nurse injecting the needle but she just said, "don't be so sensitive". A different nurse then noticed my arm swelling up and said, "she has to go to the hospital right away". At the hospital, the blood tests confirmed that I had contracted septicaemia, and I remained in the hospital for two weeks.

63. Some of my symptoms of septicaemia included freezing as though in shock whenever I blinked. It felt like I was having a stroke. On one occasion, I bruised my ribs from where I flung myself off the bed as I went to turn off my alarm. It was disorientating. On one occasion, thought to a result of the MRSA, I suffered a seizure whilst in Southmead Hospital.

64. One of the major impacts was having to tell my husband that I had contracted HCV. However, he has never been tested for HCV because as mentioned, I was informed that there was only about a 1% chance of him contracting it. It was a difficult conversation and there is an element of shame and self-doubt with these things but he was fine with it and has been a tower of strength.

65. When I discovered I had contracted HCV, I decided to have an operation to be sterilised because I would not want to put a child through that. The potential risk of the child being born with the infection was too much to contemplate. It was not an easy decision to make and something I wrestled my conscience with. Luckily, this decision did not have a massive impact on my marriage because my husband has three other children from a previous relationship.

66. Facing stigma from my family and friends never really concerned me. My mum is a bit more outgoing than I am and had a habit of announcing that I had been diagnosed with HCV. On one occasion, we were having drinks with friends, and she made a big deal about my illness which meant I was forced to tell them about my diagnosis. There was no stigma, and friends have generally been supportive. It is still not something I would typically announce. It did not have a negative impact on my relationship with my mother.

67. I am still careful around blood and take precautions when I cut myself even though I have been cured. It is a consequence of having been infected – you never want to take the chance of putting another at risk.

68. I always inform medical personnel whenever I am in the hospital, and they have to take blood. In 1996 or 1997, I had to have a cystoscopy under general anaesthetic at Southmead Hospital. When I came around after the operation, the doctor came to see me and told me that he had not finished the operation. He said, "it looks like your tubes are constrained, which means they are squeezed up. I am not going any further because I do not want to put myself, my life and my career at risk, with what you've got". He added that my kidneys were failing anyway, even though this procedure had nothing to do with my kidneys. It was so callous as if I was not deserving of treatment because of my infection.

69. I was devastated at what he said. I had never been treated like that before. It was hurtful made me feel so stupid, and I felt disgusted with myself. I was in tears when I told my brother what he had said, and my brother made a complaint about him to Dr Burton. I believe that Dr Burton had a strong word with the culprit and it was left at that.

70. That particular procedure was only completed about two months ago, 20 years on. The delay in having this operation led to increased bladder problems, and I have been prone to contracting infections over the years. I remember having a urinary infection for about two years, and they kept giving me antibiotics for this, but the medications were only getting rid of the symptoms and not dealing with the root cause of the problem.

71. I have not had problems with any other medical professionals, such as dentists.

72. My HCV diagnosis has not had a great impact on my family life. When my son was growing up, he was a bit of a lad's lad, but he did not suffer from any stigma by association. Possibly, I didn't have the time to devote to him that I could have had without ongoing medical problems. However, I disciplined him, and he straightened out. He is a successful

man now, and I have a grandson, and I still kiss him. He has no concerns about being in close contact with me nor for the child to be so.

73. I believe my mum may have been upset on my behalf, specifically watching me during that incident when I received treatment with Ribavirin. She had to take me to the hospital, and she said she was livid at the time at the doctor's attitude, which had been like, "she doesn't look too well", instead of doing something about it. The lack of contrition and failure to accept responsibility annoyed her and watching me suffer and the potential threat of death that the mistake offered must have got to her.

74. My mum may also have worried about my ill health when I was younger, but I wouldn't know. She was raising five children, so she had a lot to deal with and just got on with it. We do have a bit of a strained relationship partly caused by my illnesses over the years.

75. I tend to put a brave face up for my family, so if I do not appear worried, they are fine. I tend to transfer all my fears and worries on to my husband and I know he worries about me. He used to accompany me to some appointments when I was having HCV treatment. However, I attended the appointment for the results of the first round of HCV treatment on my own.

76. When I was having treatment, my mother-in-law told me that my husband had been so upset that he came to her house in tears. So, she had an idea of the impact on my husband because he confided in her. Sadly, she has since passed away. He would never burden me with his concerns but through her I was aware of the impact it was having on him.

77. I have three brothers, and my brother, born following me, gets quite worried about me. He keeps up to date with what's going on with my health, carries out research etc. He has always wanted me to go for private healthcare instead of the NHS.

78. When my husband and I got together, he had a lot of money. We decided not to get life insurance because the premiums went through the roof because of my health conditions, especially with HCV added to it.

79. We travelled to Australia for about three weeks, and I declared on the travel insurance forms that I had HCV, renal failure and skin cancer. The insurance fee was about £90. While in Australia, I had to stay in hospital for about three days because of a chest infection, although all I needed was antibiotics and fluids. I also had to pay for the prescriptions.

80. There have been many jobs I could not apply for due to my ill health.

81. I worked for my husband for many years doing admin and secretarial work, and it had the added benefit of being flexible. However, I can no longer do this because of the state of my fingers and joints, which means I can no longer type.

82. I am not allowed to donate blood, and I believe this is due to the first kidney transplant operation.

83. My view in life is if I keep worrying about things, I will make myself ill, so I just get on with it.

Section 6. Treatment/Care/Support

84. I was offered psychological support by Southmead Hospital, and I saw a psychologist. I do not think it was related to the diagnosis with HCV. I believe it was after completing my second round of HCV treatment and due to the fact that I would now have to go on dialysis because of kidney failure.

85. It is hard to remember, but I believe I went once or twice. I don't recall it being beneficial. I like to keep things in little boxes and forget about them until I have to deal with them.

Section 7. Financial Assistance

86. I found out about the Skipton Fund in 2010 through a letter from the Fund addressed to me at home. The letter explained that the Fund was aware I had contracted HCV, and it was sent along with forms to apply for financial support. I don't know how they got my details in the first place.

87. I completed the forms with the assistance of my GP and Dr Burton at the renal unit, who signed the form. My understanding is that Dr Burton confirmed that I had contracted HCV through the infected tissue or kidney during my transplant operation in 1981.

88. The application was approved, and I received a lump sum of £25,000 and monthly support of approximately £300. I don't recall there being any waiver with the award.

89. I currently receive support from the English Infected Blood Support Scheme (EIBSS). I believe I had to sign forms to switch over to the EIBSS after the Skipton Fund was no longer operational.

90. In 2022, I received a £30,000 top-up from the EIBSS. I believe this was to bring my payments in line with what others had received in Scotland.

91. I also receive monthly support from the EIBSS, which has gradually increased from £500 to £1500.

92. I also receive Personal Independence Payments/ Disability Living Allowance of around £234 monthly. I am unfit to work, but I am not considered disabled even though I will never get well. I am resigned to that now.

93. The only time I have ever received disability support payments was when I was on dialysis.

Section 8. Other Issues

94. I usually trust and believe doctors and do as I am told. I did not realise the drug I was taking was promoting skin cancer because nobody had informed me. there was never any mention that it may have such a side effect. – I think there should have been. I could have been given a choice.

95. I am not concerned about compensation because I would have died as a baby if it was not for the NHS. This has only changed my view of the Bristol Royal Infirmary and the local health Trust.

96. It was necessary for me to have the transplant operation in 1981, and as far as I understand, at the time, many medical professionals were not aware of HCV and that blood and blood products were contaminated. As I said it seemed they were more concerned with MRSA and other types of infection that you can pick up in hospital.

97. If it turns out that they knew it was contaminated and did not inform people, I would be pretty angry about it, but at present, I am not upset because no one knew. I would feel the same about their knowledge about the side effects of the HCV treatment. If they knew they were that severe and did not inform people, I would be quite angry to find that out.

98. I would have liked more information about the mistake that was made when I was told to take Ribavirin. There was the apology but little else. I just hope that no one else suffered the same fate as I did.

99. Even now, it is easier for family and friends to be upset on my behalf rather than for me to get upset. I just try to get on with it as best I can as

it is up to you to make the most of your life for those loved ones around you, especially those who stood by you and provided support.

Statement of Truth

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

Signed GRO-C

Dated 2ND OCTOBER 2022