Name: Christine Simpson

Statement

No.: WITN5898001

Exhibits: Nil

Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF CHRISTINE SIMPSON

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

I, Christine Simpson, will say as follows: -

Section 1. Introduction

1. My name is Christine Simpson. I was born on GRO-C GRO-C 1953 and my address is known to the Inquiry. I am married and I have two grown-up children. I am retired but I do some house-sitting work occasionally. I currently live in a village in Suffolk with my husband, Pat.

2. I intend to discuss my infection with Hepatitis C (HCV), which I contracted from a blood transfusion following the birth of my first child.

3. This witness statement has been provided without the benefit of access to my full medical records.

4. I can confirm that I have chosen not to have legal representation and the Inquiry Investigator has explained the anonymity process to me. My family has not been involved in prior litigation.

5. I can also confirm that the Inquiry Investigator has explained the 'Right to Reply' procedure, and that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.

6. I wish to acknowledge that naturally as time passes, memories can fade. I have been able to provide approximate timeframes for matters based on life events. However I can only recall to the best of my ability, and these timeframes should be accepted as 'near to' rather than precise dates.

Section 2. How Infected

7. I was born and brought up in a small village in Suffolk. I have had various jobs in my working life, including cleaning, working in a pub. Although I am now retired, I still do some housesitting work with my husband.

8. My husband Pat and I got married in 1975, and we went on to have two children; a girl, Tanya, and a boy, Benjamin.

9. I had my first child, Tanya, on GRO-C 1977 at West Suffolk Hospital, Bury St Edmunds.

10. It was a very long labour. I went into labour on GRO-C GRO-C and it lasted all night and then all of the following day. During the birth, I lost a lot of blood.

11. During my pregnancy, I had already been told my iron count was very low. A combination of already-low iron levels and then the blood loss meant I required a transfusion.

12. I was given two pints of blood the day after my daughter was born, so on GRO-C 1977.

13. I felt fine and we were discharged home, where my husband and I embarked on normal family life with our new baby.

14. Seven years later, our son Benjamin was born, and we carried on life a family of four.

15. In the mid 2000s, it was discovered I had a low platelet count. I was placed under the care of West Suffolk Hospital, Bury St Edmunds for this.

16. I was asked to go to the hospital once a month for them to monitor my platelet counts. My platelet counts sometimes fluctuated a bit but remained low throughout this time. I spent a year or so going for these monthly appointments, and during this time I was checked and tested for lots of different things to try to get to the bottom of what was causing the low platelet count.

17. In 2008, after around a year of these appointments, all of a sudden, one of the doctors who I had been seeing told me I had HCV.

18. It came as a huge shock. We did discuss the possibility of me having acquired the infection via a transfusion early on, but because that had happened so long ago, the doctor thought it was doubtful. It was very hard to process what I was being told.

19. It was 31 years from the time my daughter was born to finding out about the HCV, which is a very long time.

20. I have not had any other transfusions. I do not have any tattoos I had my ear piercing done at doctors when I was 12 years old as was common practice then. I have never used IV drugs or have any other high risk factors.

Section 3. Other Infections

21. During the time I was being monitored for my low platelet count, I was tested for lots of things, and I have not been infected with anything else that I know of.

Section 4. Consent

22. I was never told about risks of transfusion. I was aware I needed the blood at the time, and that was it really.

23. I do not believe I was ever tested without my consent. I gave my consent for tests to be carried out.

24. I have never been part of a research programme.

Section 5. Impact

25. My diagnosis came as a shock for me and my family, and it was very worrying when I first found out about it. I found it very difficult to comprehend and take on board. It had a huge effect on me mentally.

26. My children were also very distressed. Suddenly out of nowhere I had this life-threatening infection with risks of passing to others, including them and my husband.

27. GRO-C
GRO-C My husband and son were both deemed to be quite high risk, as my son was born after my transfusion so I could have passed it to him in pregnancy or childbirth. It was very stressful while we were waiting for the result.

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29. After I was diagnosed as having HCV, I was

considered 'high risk' in respect of other medical care. I had to inform everyone medical, which felt weird.

30. I also had to wear a red wristband when I attended hospital. I think this was at West Suffolk Hospital, but can't remember for sure whether it was there or at Addenbrookes. I definitely recall having to wear a red wristband, particularly when I had to have blood tests. I understood why they wanted to make professionals aware when they were dealing with taking blood samples or doing other quite high risk activities, however I did not like having to wear the wristband. It made me feel different to everyone else.

31. I had to tell my dentist but had no issues apart from the fact I had to tell them, and I wasn't treated any differently. I didn't have to wait until end of the day or anything like that. My dentist always wore gloves anyway, so I didn't feel any different when having dental treatment.

32. The HCV did not have any effect on my education or job prospects. In terms of work, I was able to carry on throughout, so I didn't lose money in that respect.

33. However I did have to spend lots of time travelling to Addenbrookes Hospital. I had to go to Cambridge every month as my treatment prescription only gave me a month's supply at a time. This was time consuming as its quite far from my home in Suffolk.

34. I took the treatment at home. I got on with the treatment okay, though I needed my husband's help doing the injections. It worked to clear the HCV which is the main thing.

35. I did tell people about my HCV, though this was mainly close friends. I didn't experience any issues regarding stigma.

36. I did not have any issues with insurance or travel

insurance.

Section 6. Treatment/Care/Support

37. When I was first diagnosed with HCV, I was told they couldn't deal with it at West Suffolk Hospital as they didn't have a specialist area there.

38. As a result, I was told I would have to go to Addenbrookes Hospital, Cambridge, for monitoring and treatment.

39. Once I was referred there, I was assigned a specialist nurse called Tracy, who I saw each time I went.

40. Occasionally I saw a consultant, but not very often. The majority of my appointments were with the specialist nurse.

41. The nurse was very good. She was very nice and very helpful. HCV was her specialism and she really knew her stuff. She gave me a lot of information regarding HCV. I didn't know anything about it really before that. I certainly hadn't been given any information about it before my referral to Addenbrookes.

42. I think at that time I was given adequate information to understand the infection, though I had had it in my system for a long time before learning anything about it, which was a huge worry.

43. However obviously the information couldn't have been given earlier as I didn't know I had HCV until then.

44. The specialist nurse said not to drink alcohol. I didn't really drink anyway, I only ever have the odd glass of wine with a meal, which is all I've ever

done.

45. I was told about precautions like not sharing toothbrushes or towels. I was aware HCV was spread through blood. I was also given paperwork and things to read at home as well as what I was told verbally.

46. We were a family of four and I was very concerned that I might have passed it on to my husband or children. GRO-C

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47. Once I was referred to Addenbrookes, I can't fault them with how I was treated.

48. One of my main issues is that I do think I should have been tested for HCV sooner, considering the platelet issue I was presenting with. My platelet count varied a bit, but it was consistently low for at least a year before I was finally tested for and diagnosed with HCV.

49. You rely on medical professionals to do what's correct, but I think they missed chances in my case. I would have thought HCV would have been an obvious thing to check for given the fact it can cause low platelet count, but they overlooked it for a long time.

50. When I was first diagnosed, I was told there was treatment for it, but it was not immediately available to me. I remember the nurse saying it might be a long time before I got treatment as it's so expensive.

51. I had to have two liver biopsies. I think one was before I started the treatment and one after treatment.

52. The biopsies were not pleasant at all. They involved staying in the hospital for the day. You

have to lay on your side for the rest of the day following the procedure, and then you have to sit up gradually. This is to prevent liver from bleeding. It makes for a very long and uncomfortable day in hospital.

53. I was offered treatment around a year after I found out about the HCV infection.

54. I was put on a combination of Interferon and Ribavirin for 6 months. The Interferon was injections and the Ribavirin was in tablet form.

55. I was able to have home treatment. My husband gave me the injections once a week. I still had to travel to Addenbrookes Hospital at least once a month in order to get my prescriptions as they only gave me a month's supply at a time.

56. The main thing I experienced in terms of side effects was that I would feel extremely fatigued. I remember feeling so tired and lethargic, and just not very good for the whole 6 months.

57. I can't remember anything else apart from the fatigue.

58. The specialist nurse had told me to take the injection before I went to bed, and to then take paracetamol and go to sleep. So I did this religiously. The idea was that some of the side effects would be reduced in the night. Fortunately, this seemed to help me and my side-effects were relatively mild.

59. I was doing cleaning jobs which I continued with throughout the treatment period. Therefore the treatment didn't affect my job. It wasn't a full time job, but I managed to continue.

60. I would have to come home and rest when I had finished working. We didn't do a lot else during the 6 months I was having the treatment. I didn't feel energetic enough.

61. My children were 31 and 24 when I had treatment. They were adults, but they were still living at home. They didn't need looking after, but I was still a mum and was still doing a lot for them while they were at home.

62. I'm not sure what genotype my HCV was. I only know that it was the type that needed 6 months treatment as opposed to a year-long treatment.

63. I was a lot younger than some others who have been infected and who were having treatment, and I am female, which may have helped with the treatment side of things. I remember reading somewhere about females being able to clear HCV easier, so that may have helped me.

64. The treatment was successful and I was told the HCV was no longer detectable. Luckily, I was also told that there was no lasting damage to my liver.

65. After my treatment, I was told I would have to have checks and bloods taken every couple of years by my GP, however I was discharged from Addenbrookes. I was just told they wouldn't be seeing me anymore once I'd cleared the HCV. I felt a bit like I had been dismissed.

66. I didn't agree with that decision. Neither my normal GP nor West Suffolk Hospital specialise in HCV.

67. I wasn't sure if being seen by my GP was sufficient to ensure I was still clear and I wasn't confident that it would be picked up straight away if it were to come back. My GP had openly admitted that he didn't know anything about HCV. He was quite interested in the information I had been provided with by Addenbrookes as he didn't know about it. This didn't fill me with confidence in terms of being monitored by my GP surgery after my treatment.

68. So at the time I remember being quite concerned about the future. I felt fobbed off.

69. I feel I should have been able to continue to see specialists at Addenbrookes, even if it was just one appointment every couple of years.

70. My feeling is just because the HCV is currently undetectable, that doesn't mean it won't ever come back. I want to be in the best position to fight it should it return, and I am not sure that's the case with being left under the care of people who openly admit they don't know anything about HCV.

71. I make sure I take responsibility for my monitoring. I make a point of contacting my GP at the relevant times and saying I need the blood tests and checks done. I keep on top of it. If it was left to them, I don't think my checks would actually get done.

72. I was never offered any counselling or psychological support, however I didn't feel any need for it. My family understood and I felt supported by them, that was all I needed at the time.

73. With regard to support during treatment, my side effects weren't too bad, and I just got on with it. I knew it was only for 6 months so I knew it was a set amount of time I wouldn't feel good, and I would feel better afterwards. That kept me going.

Section 7. Financial Assistance

74. I was advised by medical staff at Addenbrookes about the financial support available from the Skipton Fund.

75. I remember going to one of my appointments and being asked by two members of staff if I was aware of Skipton. I said I wasn't, and then they provided me with the details. I went away and filled out the application form.

76. I received a £20,000 lump sum first stage

payment.

77. In July 2021, I received a £30,000 lump sum. I was told this was to bring me in line with payments in Scotland.

78. Now, I receive around £19,498 per annum. There is also a winter fuel allowance of £561.

79. I can't remember anything difficult with the application process. I just filled a form in and then it was signed off by a doctor. It was fairly straightforward.

80. The hospital had my medical records which showed I had had a transfusion. I also have a record of transfusion on my pregnancy note card. There was therefore clear evidence of the transfusion.

Section 8. Other Issues

81. My main issue is that I think the doctors whose care I was under at West Suffolk Hospital should have investigated the possibility that I had HCV earlier than they did. I spent a year back and forth to hospital for various checks before I was finally tested and diagnosed.

82. HCV causes low platelet count. I would think this would mean they should have looked for it sooner as I had consistently low platelet count for a really long time, but they didn't.

83. It was 31 years from my daughter's birth and my transfusion to being diagnosed and then even longer before I started having treatment. That's a long time for someone to have HCV in their system, and was obviously a significant risk to others during the time I was completely unaware of it.

Statement of Truth

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

Signed GRO-C

Dated 7-5-2022