Witness Name: Christine Kelly
Statement No: WITN0409001
Exhibits: Nil
Dated: 2 August 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF CHRISTINE KELLY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 3 May 2019.

I, Christine Kelly, will say as follows: -

Section 1. Introduction

1. My name is Christine Kelly. My date of birth is GRO-C 1961 and my address is known to the Inquiry. I have been married to my husband for 39 years and we have 4 children.

2. I intend to speak about my infection with Hepatitis C by blood transfusion. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my family and our lives together.

Section 2. How Infected

3. My infection happened when I gave birth to my fourth child in 1989. I did not have any issues with my first three children's birth's.

4. On GRO-C 1989, I gave birth to my fourth child, a daughter, at Hope Hospital in Salford. At the time of the birth I was 28 years old. The birth was a difficult one and I had a haemorrhage immediately after. The nurses told me that I needed blood because of the haemorrhage.

5. At the time, I was aware of Aids because I had been hearing about it a lot in the news. I did not want to be given blood because I feared Aids. Before I passed out, I remember telling the nurses that I did not want any blood.

6. The next thing I remember is waking up from a sleep. I believe that I must have passed out. I am now aware that I was put under anaesthetic to receive surgery for the haemorrhage.

7. When I came to, I was told by my sister that I had been given a blood transfusion. I believe that I was given about 2 pints of blood.

8. I do not remember ever telling the nurses that I gave them permission to give me the blood transfusion. I only remember telling them before I passed out that I did not want any blood.

9. As far as I am aware, this is the only blood transfusion I have ever received.

10. I was not made aware of the risk of contracting any infections prior to receiving the transfusion.

11. After the transfusion, I was discharged from hospital and I carried on life as normal.

12. When I got into my forties, I began to notice that I did not feel well. I constantly felt physically drained, sick and tired all of the time. I was experiencing aching all over my body. I did not know what was wrong with me, but I knew that I just wasn't right and did not feel like myself. I could only put it down to getting older. I thought that getting older, and having 4 kids, this was just what it was like.

13. At one point I developed a lump on my wrist. I went to see the locum doctor at my GP surgery at the time, which was GRO-C Surgery. I had never seen the same GP on a consistent basis at my GP surgery as there are only locum GP's at the surgery.

14. A nurse at the surgery took my bloods and told me that I had tested positive to Rheumatoid Arthritis.

15. I was then referred to a specialist who was a Rheumatologist by the name of Doctor O'Neil, at Hope Hospital. A couple of weeks after my initial meeting with the Rheumatologist, he asked me to come back for some more blood tests. I was not told what these blood tests were for.

16. I later received a letter from the Rheumatologist informing me that I should go and see my GP, as he thought that I had a viral form of Hepatitis.

17. I went to my locum GP and they took more bloods from me. I was told that they would need to send me to Manchester Royal Infirmary as Hope Hospital did not deal with Hepatitis.

18. A couple of weeks after these bloods, I saw another locum GP at my GP surgery and he told me words to the effect of, "you don't have Hepatitis B, so you have nothing to worry about, come back if you turn yellow".

19. At this stage I was not provided with any information about Hepatitis or how to manage an infection. I didn't even know that there were other types of Hepatitis besides Hepatitis B, so I thought nothing was wrong.

20. Although the locum GP told me that I did not have Hepatitis B, I was still feeling off. I was still experiencing aching all over my body, and I just didn't feel right. I did not know what it was, I just knew that I weren't right. I kept thinking that it was just my age, and that was all I could put it down to. As I mentioned above, I thought that at my age, and having 4 kids, this was just what it was like.

21. I was diagnosed with Hepatitis C in around 2002. I cannot recall the exact date of my diagnosis. I remember that about 14 months after I went to see the locum GP who told me that I did not have Hepatitis B, I went back to see a locum GP at my GP surgery sometime in 2002 by the name of GRO-D

22. I went back to the GP in 2002 as I was sick and tired of constantly not feeling well. I explained this to GRO-D and he responded with words to the effect of "what do you expect, you have Hepatitis C". I said to him, "no I haven't', and he told me that the surgery had sent me a letter informing me of the diagnosis. I told him that I had not received any letter from them informing me that I had Hepatitis C.

23. GRO-D then exited the room and came back with a letter which he threw onto the table in front of me. He told me that the letter was sent to me 14 months ago. I told him words to the effect of that I had never received the letter, and that if I had received such a letter I would have known.

24. This exchange with GRO-D was very heated. I found his attitude to be very obnoxious and aggressive, and I feel that he was very rude to me.

25. I thought he was an awful, awful man and I did not want to see him again. After my consultation with GRO-D I cried and cried. I thought I was going to die.

26. I have lived at the same address since around 1997, and still currently reside there, so I would have definitely received the letter at my address and I would have seen it. I can confirm that I never received this letter he was referring to.

27. After this, I went to see a different locum GP, I don't recall his name, who confirmed that I did have Hepatitis C. He sent me to a Gastroenterology Specialist called Doctor Babbs at Hope Hospital. I'm not sure when I started seeing Doctor Babbs. I think it was around late 2005.

28. Doctor Babbs was a lovely man. I did not know anything about Hepatitis C, and so I did not know how I had contracted it. Doctor Babbs asked me a series of questions. These included: whether I had any piercings or tattoos, whether I had used intravenous drugs and the number of sexual partners I had. My answer was no to all of these questions and I have only had one partner during my lifetime, being my husband, so I could not figure out how I had been infected.

29. Doctor Babbs asked whether I had ever received a blood transfusion. This was the only thing that I could answer yes to. Doctor Babbs told me that I had probably received contaminated blood.

30. It was after this that I knew that the only way I could have contracted the Hepatitis C would have been through the blood transfusion I received after the birth of my daughter. Therefore, I believe my infection was because of the blood transfusion.

31. In around early 2006, Doctor Babbs sent me for a biopsy to see whether the Hepatitis C virus was still active. He said that sometimes the virus could clear up.

32. The results of the biopsy were that the virus was still active. At this point I had received no treatment for the virus at all. Doctor Babbs informed me that he could not treat me anymore as he did not specialise in treating Hepatitis C, and referred me to a Doctor Harry at Manchester Royal Infirmary.

33. It took about 12 months for me to receive an appointment with Doctor Harry. I do not know why it took so long to receive an appointment.

34. In around early 2007, I was able to see Doctor Harry. I then waited until around December 2007 to commence my treatment. My treatment under Doctor Harry consisted of receiving Interferon injections and having Ribavirin tablets for 48 weeks.

35. At this point, I was still not given any adequate information about the virus by any of the medical professionals. I didn't realise that if I left my razor out and my daughter used it, the virus could be passed on to her.

36. I believe that I was not provided with adequate information by any of the medical professionals to help me understand and manage the Hepatitis C infection. At each stage of the diagnosis, after seeing each Doctor, I was just left to myself and was told nothing. I was not told what Hepatitis C would do to me. I think it's disgusting that you are just left hanging, that you are left in the dark.

37. Even Doctor Babbs, who I believe was a lovely man and a good Doctor, did not provide me with any information about Hepatitis C. He could only tell me that I had probably contracted it from the blood transfusion.

38. I did not look up any information on the internet about Hepatitis C. The husband of an old lady who I knew, and was friendly with at the time, made a point of finding out everything about Hepatitis C for me. He printed out all of the information and gave it to me.

39. I felt that I could talk to this lady and her husband about anything. My own mother had passed away around 30 years before and my father was still alive, however he was very ill and I felt that I could not talk to him as I did not want to trouble him.

40. I was not told anything at all about the risk of others being infected as a result of my infection. As I mentioned before, I didn't know that if I left my razor out and my daughter used it, that this could pass on the infection to her. I didn't know any of this.

Section 3. Other Infections

41. As far as I am aware, I did not receive any other infection besides Hepatitis C.

Section 4. Consent

42. I do not believe that I consented to having the blood transfusion after the birth of my daughter on GRO-C 1989. This is because I remember telling the nurses before I passed out that I did not want blood. The next thing I remember is waking up and being told that I had received a blood transfusion.

43. I do not remember ever saying yes to the blood transfusion.

Section 5. Impact

Physical and Mental impact of Hepatitis C

44. On being diagnosed with Hepatitis C, I thought that I was going to die, and as mentioned before I came home from my appointment with GRO-D and cried.

45. The only way I can describe the physical effects of the Hepatitis C infection are that I just wasn't feeling right. My joints ached and I had headaches and was so tired. I felt like I constantly had a flu all year round. I felt drained and didn't have the energy to do the things that I normally did.

46. As I have mentioned above, I thought that this was just my age and the result of having 4 kids to look after. I thought that I may be menopausing in my 40's, as there was no other reason for me to be feeling like I was. I had never felt anything like I was feeling before.

47. I remember when my youngest child was in high school, I just couldn't be bothered doing anything and I just wasn't myself. To be honest, I thought it may have also been stress.

48. I responded to my treatment with Interferon and Ribavirin, and the Doctors told me that although my Hepatitis C is a sustained viral response, I now have less

than 10% of the infection in my body. They have not told me that the Hepatitis C has gone, just that the amount is so low that they cannot trace it.

49. Although I responded to my treatment, the Doctors told me that the Hepatitis had already caused damage to my liver. I was told that the damage was already done and that I had stage 5 cirrhosis.

50. I still have the cirrhosis today, and I need to have liver scans twice a year as well as cancer tests. I also have an endoscopy every 1 to 2 years because I am always sick, so the Doctors want to make sure that there is nothing wrong with my stomach. The cancer tests that I have are on my liver, testing for liver cancer every 6 months. They are called carcinoma something, I'm not sure of their exact name. They also check my kidneys to make sure there is nothing wrong with them.

51. I have been going to Manchester Royal Infirmary to have all of these ongoing tests for the last 12 years.

52. I am not currently on any medication for Hepatitis C, as they cannot give me medication anymore. This is because the amount of Hepatitis C in my body cannot be traced anymore. The Doctors now just monitor me, and I have to attend the regular medical appointments above. So, it is really just a waiting game now.

53. I am waiting for them to tell me any day now, "Mrs Kelly, you have cancer".

54. I absolutely hate going for my medical appointments, and I feel sick when the time arrives for them. I do not like any of my family to attend the appointments with me. Nine times out of ten I am physically sick when I arrive home from my medical appointments.

55. I usually have to wait around 6 months for results whenever I go to an appointment and have tests. I have to see the Doctor in person 6 months after

the tests to get the results. The time spent waiting is not a nice feeling and makes me very anxious.

56. Although the Doctors have told me that the virus is not detectable in my body anymore, I still feel like I have it. I still feel that it is in the blood that I received that is pumping around my body. The Doctors have told me that it is all in my head. I feel that these thoughts and feelings will never go away and that there is nothing anyone can say or do to get them out of my head. I still get panicked if I cut myself and any of my grandchildren come next to me.

Physical and mental impact of the treatment

57. As I have already mentioned, I started my treatment for Hepatitis C in around December 2007.

58. I received injections of Interferon and took Ribavirin tablets. The nurse told me that the treatment was not very nice and that I may not tolerate it.

59. I had the injections for 48 weeks. I had the first one at hospital, and after that I would administer the injections myself at home. I would have one injection of Interferon per week, and would take 9 Ribavirin tablets per day.

60. I was sick every single day that I had the injections, it was an absolutely awful treatment. I was always sick after the injections, I could guarantee that I would be violently ill the morning after an injection. The tablets gave me severe headaches.

61. I lost weight during the treatment, and my hair and some of my teeth fell out. After the first 6 months, I wanted to stop the treatment because of these side-effects. It was absolutely horrendous.

62. When I was in the shower and washed my hair, my hair would just come off. I lost all of the hair at the back of my head and had a big bald patch. I would break down crying when my hair fell out.

63. I couldn't brush my hair because as soon as I put a brush through it, it would just fall away. I managed to clip my hair up in a way that people could not see my bald patch.

64. I had a friend who was a hairdresser. I would go to see her every month and she would help me fix my hair so that the bald patch was not visible.

65. My hair stopped falling out as soon as the treatment ceased, but the feeling constantly sick continued for a good 6 months after.

66. I was very moody during the treatment. My moods were up and down. One minute I was ok, the next I was in tears.

67. I didn't have time to think about myself, I just wanted the treatment to be over. The only thing that kept me going during this time was my children and grandchildren. At the time of the treatment, my daughter was pregnant with her second child and I just wanted to get through the treatment for them.

68. My moods would ease for a couple of days before the next injection and would start up again once I received the injection.

69. I did not receive any support or advice from any of the medical professionals regarding the emotional impact the treatment was having on me.

70. All of the teeth at the back of my mouth fell out, and I believe this was due to the treatment as I had perfect teeth before the treatment.

71. I cannot fight off illnesses as well as I used to. It now takes me around 2 months to fight off a flu. I believe this is due to the effects of the Hepatitis and the treatment on my body.

72. As I mentioned above, although the treatment cleared the Hepatitis C, the infection caused lasting damage to my liver, and to this day I am in and out of hospital with regular appointments to monitor my liver.

73. Initially, when one of the nurses told me how much Hepatitis was in my body, she told me that I should be dead with the amount that I had. She told me that my count was 56 million and that the limit was 25 million. I have never been a drinker or smoker, and I believe that this is what has helped me get through the treatment and has kept me here today.

Impact on Family Members

74. I did not initially tell my family that I had Hepatitis C. The last thing I wanted to do was to worry my family.
75. However, just before I commenced my treatment I told them, as it would be inevitable that they would see me injecting myself at home and they would see all of the pills I was taking, which I had to keep in the fridge. I did not tell them until I couldn't get away with not telling them anymore.

76. My children were teenagers at the time I was receiving treatment. When I told them what was going on they were devastated and they thought I would die before my time.

77. My daughter blamed herself for the infection and said that if I hadn't of given birth to her I would not have got the infection.

78. I never told my father about the infection as he was very ill at the time and I did not want to worry him. I felt like I couldn't talk to him about it.

79. When I told my husband that I had Hepatitis C, he thought that I had been sleeping around and it nearly ended our marriage. He told me words to the effect of that "you only get things like that if you sleep around". It put great strain on the marriage. However, we stayed together and we are still together today.

Financial Impact

80. I did not tell anyone else about my infection besides my family, the old lady and her husband who were my friends, and my employer at the time.

81. Before and during my treatment, I worked as a house keeper for a wealthy family. I ended up telling my boss about my infection as I was taking so many sick days because of the side effects of the treatment. I was so tired all the time, I couldn't sleep, my joints ached, my body ached from head to toe and I had trouble getting up and down the stairs.

82. I could only really work part-time during my treatment as I was too sick. During the time that I did not work because I was sick I was not paid, and eventually they gave my job to someone else.

83. I don't know whether I lost my job because I told my boss about the infection, but I believe that this, along with all of the sick days I was taking, was the reason why I lost my job.

84. I have not worked since I received my treatment because I am constantly unwell and tired. I have no energy, am constantly tired, the pain in my joints drives me insane, I have seriously painful knees and I can't sleep at night because I ache from head to toe. I can't remember the last time I had a decent night's sleep. I believe these are the ongoing effects of the treatment on my body.

85. My husband had a GRO-C at the age of 50 and needed a GRO-C He was therefore out of work for a while, and with me being unable to work, it has hit us hard financially.

Stigma

86. As I mentioned earlier, I do not always see the same GP at my GP surgery, as the GP's at the surgery are locum GP's.

87. Each time I would go to the GP I would receive a different locum GP. The GP would bring up my records on the computer and have a look at them.

88. On one occasion, the locum GP looked at my record on the computer and said, "I see you have cirrhosis…are you a functioning alcoholic?". Another locum told me that I should use clean needles after seeing that I had Hepatitis.

89. This made me feel ashamed. I feel like I am living with a stigma as people assume you are an alcoholic or a drug addict if you have Hepatitis.

90. During one of my check-ups, the locum said to me words to the effect of, "I don't understand why we still need to see people like you". I assume he was referring to alcoholics, and that he assumed that I was an alcoholic. These comments upset me.

91. Eventually I got fed up with Doctors assuming I was an alcoholic or drug addict because I had Hepatitis, and I asked my consultant, Doctor Prince, at Manchester Royal Infirmary to specify on my medical reports and letters to other Doctors that I had cirrhosis because of the Hepatitis I had contracted through contaminated blood.

92. The only reason why I go to the Doctor nowadays is because I have to for my regular check-ups. From the way I have been treated by Doctors, I have lost all trust in them. There has also been a couple of occasions of misdiagnosis of my family members by Doctors, which has also caused me and my family to completely lose trust in Doctors.

93. I have never been abroad as my husband doesn't like to fly. My eldest daughter wants to go on a trip overseas, but if I have to disclose that I have had Hepatitis to get insurance, then I don't want to go away.

Section 6. Treatment/Care/Support

94. The main difficulties and obstacles I experienced in obtaining treatment, care and support in consequence of being infected with Hepatitis C were that it took a long time for me to receive treatment from when I was initially diagnosed with Hepatitis C. It took around a year from my diagnosis to receive the treatment I needed.

95. I don't know why there was this delay. I suppose it is just the long waiting lists for treatment with the NHS.

96. Counselling and psychological support was never made available to me when I was infected or during my treatment.

97. I wouldn't call what I suffered depression, however, the medical professionals I dealt with never offered me any kind of emotional or psychological help and support.

Section 7. Financial Assistance

98. Doctor Babbs put me in touch with the Skipton Fund and helped me fill out the forms for the initial payment. He was very helpful.

99. I received an initial payment of £20,000 from the Skipton Fund in 2006. When I received this initial payment from the Skipton Fund, I was made to sign a form. I was not able to receive the payment unless I signed the form. The form was written in complex legal language and it was very hard for me to understand. All I could understand was that it said something like the government was not to blame for my infection.

100. I just signed the form as I was in financial need and had 4 kids at home.

101. I got the second stage payment of £25,000 about 18 months later as I was diagnosed with cirrhosis.

102. Around the period between 2010-13, I'm not sure exactly when, I received a letter from Doctor O'Neil, the Rheumatologist at Hope Hospital, telling me that the surgery had received a letter from the Skipton Fund asking about my whereabouts as they could not find me.

103. I got in touch with the Skipton Fund and the man I spoke to told me that they had been trying to contact me as they owed me money. He said they couldn't contact me. I told him I had been living at the same address and was with the

same bank the whole time. He informed me that the stage 2 payment had increased, so I was owed more money. I ended up receiving about £67,000 because the stage 2 payment had increased.

104. Someone from the Caxton Foundation got in touch with me and I received some payments from them as I was registered with the Skipton Fund. However, I only got 4-5 payments from the Caxton Foundation. The payments didn't last long. I am currently still on a stage 2 payment from the Skipton Fund and I am paid £1536 a month.

105. I don't understand why the Skipton Fund delayed in notifying me that I was owed the additional money. I feel like they did not bother or try very hard to contact me to let me know that I was owed the extra money. The money would have been a very big help to me and my family over the years as I couldn't work after my treatment, my husband could not work because of his GRO-C GRO-C and we were putting out daughter through university.

Section 8. Other Issues

106. Although I responded to the treatment for my Hepatitis virus, and the virus is now not detectable in my body, as I mentioned earlier I still feel like this awful virus is in my body. I feel like it is still in my blood, pumping around my body, because the contaminated blood was put into my body.

107. I felt this way after I finished my treatment too, and as I mentioned earlier, the Doctor told me that it was all in my head. I feel as though this feeling never goes away. I still get panicked whenever I cut myself and my grandchildren come next to me. I can't think of anything that anyone can do or say to get this feeling out of my head.

108. I have lost all trust in Doctors and the medical profession because of the errors that were made by the Doctors in notifying me of my diagnosis, and the way the Doctors have treated me over the years when they learned I had Hepatitis C.

109. Whenever the time of the year comes around that I have to go to the Doctors for my appointments I feel physically sick and am always physically sick after my appointments. I absolutely hate going to the Doctor and never bring any of my family with me.

Statement of Truth

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

Signed GRO-C

Dated 2 August 2019