Witness Name: Claire Alison Cooke
Statement No.: WITN0157001
Exhibits: **WITN0157002 - 6**
Dated: 25 March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF CLAIRE ALISON COOKE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 29 January 2019.

I, Claire Alison Cooke, will say as follows: -

Section 1. Introduction

1. My name is Claire Alison Cooke. My date of birth is GRO-C 1963 and my address is known to the inquiry. I am living with my Partner of 2 years and my 12 year old daughter. I used to work in the insurance sector however I do not work anymore due to my heart and cirrhosis of the liver.

2. I intend to speak about my infection with the Hepatitis C virus, which I contracted from blood transfusions. In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment received and the impact it had on my life.

3. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with drafting my statement.

Section 2. How Infected

4. I was born with a congenital heart defect - tricuspid atresia with hypoplastic right ventricle and pulmonary atresia - which means I only have three chambers instead of four in my heart. My parents found out from Bristol Children's Hospital when I was 6 weeks old - they said that I was a very rare case.

5. In 1965, I was given a blood transfusion at Bristol Children's Hospital during a Brock operation, which involved sewing up holes in my heart. Dr. Jordan was the Cardiac Surgeon at the time. My parents were not informed of any risks of infection prior to the blood transfusion. I tried to get records of this blood transfusion but I was told they were destroyed after 25 years.

6. The doctors at Bristol Children's Hospital said they could not help any further with my heart condition and so I was sent to Great Ormond Street Hospital. I cannot recall exactly when this transfer took place.

7. In 1970 and 1974, I had operations on my heart at Great Ormond Street Hospital. Once again, I was given blood transfusions (**WITN0157002 and WITN0157003**) and my parents were not informed of any risks of infection.

8. On 24 April 1975, I had a Fontan operation on my heart. Again, I received a blood transfusion (**WITN0157004**) and the risks of infection were not explained to my parents beforehand. Dr. Stark was the Cardiac Consultant at the time and Mr. Bonham Carter was another. All the Surgeons I had would have been the top ones in the world at Great Ormond Street.

9. In 2014 I had two cataract procedures. During the second cataract procedure, a needle pricked the Nurse's finger. Due to this, we both had

blood tests carried out at Cheltenham Hospital to check for HIV - I am not certain about the date but I believe this was around April 2014.

10. In May 2014, I was on holiday when my GP telephoned to tell me that I did not have HIV but I have Hepatitis C. I replied, 'What's that?' I had heard of it but I did not know what was implied. He did not explain what Hepatitis C was at any time. He simply said that I needed to go for more tests.

11. When I think back to 2012, I kept going to the Doctor about feeling tired and depressed. I am a strong person but I kept crying over small things. The Doctor said that I had depression but I did not have anything to be depressed about. He also said that I may have an overactive thyroid. Nobody said 'You have had a blood transfusion, maybe you have Hepatitis'. When I think back I had these signs for about 2-3 years and I may not have known about Hepatitis C unless the Nurse pricked her finger.

12. After being told about the Hepatitis, I went to see my GP - I was very angry. I told my GP that all surgeries were given guidance to offer Hepatitis C tests to those people who received a blood transfusion. His response was that he did not know anything - I am not sure if the guidance had not been passed down. It was quite a worry. I think there could be other people like me who have been infected and don't know.

13. Due to this conversation with my GP, I wrote to Neil Carmichael, MP for Stroud Valleys and Vale. I received a response on 9 October 2015, which confirmed that the guidance had been issued to GPs (**WITN0157005)**.

14. My mother then wrote to the Practice Manager of the GP's surgery on 23 October 2015. After receiving no response, she sent an email on 24 November 2015. She received a response from the Practice Manager on 3 December 2015, which said that the surgery did not receive any correspondence, which said that they needed to screen all patients who

could potentially have had blood transfusions prior to 1991 (**WITN0157006**).

15. Around 4-6 weeks after the GP's telephone call, I was referred to Gloucester Royal Hospital. I was under the care of Liver Specialist Nurse, Kate Pritchard.

16. Nurse Pritchard explained the Hepatitis C virus and how I probably got it - I told her that I had not taken drugs but I received blood transfusions in the past.

17. She explained that I needed treatment to clear Hepatitis C, but I was limited to certain drugs because I was taking Warfarin (blood thinning drug) for my heart condition.

18. In terms of managing the infection, she told me not to have dairy products and alcohol. I asked her about the risk of transmission through unprotected sex and she said that the risk was low. Nurse Pritchard also said that if I had a cut, then I should not ask anyone to put a plaster on an open wound. Generally, she told me to consider my wellbeing and to exercise. It was hard because my daughter was eight at the time.

19. Although I then felt that I knew enough about Hepatitis, I was told that if I thought of anything else, I could call the Nurses on their mobile numbers.

Section 3. Other Infections

20. I have been infected with Hepatitis C only.

Section 4. Consent

21. I consented to the HIV test but I did not consent to the Hepatitis C test that was carried out at the same time.

22. As far as I am aware, I have not had any other tests carried out on me without my consent.

23. I consented to the treatment for Hepatitis C.

Section 5. Impact

Mental and physical effects

24. During the first few months of the diagnosis, I was angry and very worried. I felt that it was a death sentence. I felt dirty, even though I did not take drugs through needles, as I thought that was how some got it. I did not know enough and there was no one else to talk to about it. I did use some forums, which I found helpful, even if I was just telling people what I was doing.

25. As time went on, I suffered from depression, I was frightened and I was bad tempered. I can deal with a bad heart as it has been with me from birth but this was something else. It totally messed up my life.

26. I was also quite worried about going out in a car because when I was depressed I had suicidal thoughts - I considered whether I should just drive into a house. However when I had those thoughts, I reminded myself that I have my daughter.

27. Physically, I felt tired, I couldn't sleep and I did not eat very well. I used to occasionally go clubbing and to the pub for chats but I couldn't do that at the time as I did not feel like going out. I also felt very cold - I had heating on in the summer but I still found it cold.

Further medical complications

28. I was diagnosed with cirrhosis of the liver 4 months after finding out about Hepatitis C.

29. In 2018, a mole was found on my liver. I am currently awaiting results from the CT scan of the mole. I think that if anything kills me, it will be my liver than my heart.

30. I do not know enough about cirrhosis as I have been told different things about it. I remember seeing a male doctor who talked about drinking and having a normal alcohol level but my Nurse said that cannot be correct. I have had to watch my alcohol intake.

31. I try not to think of cancer. I have a check-up every 6 months and I have a camera down my throat every 2 years - I go every time and hope it has not got worse.

Treatment

32. I started the treatment for Hepatitis C in October 2015 at Gloucester Royal Hospital. I was put on a 12-week course consisting of Harvoni tablets (90/400mg) and Ribavarin tablets (600mb) daily.

33. The side effects were numerous. I started off feeling spaced out, tired and depressed. I could go out but then forget what I went out for. All I wanted to do was to lie in bed – I've never been like that before even after my heart operations. I felt like a zombie. My daughter kept asking if I was going to die - she had to put up with quite a bit.

34. I called Nurse Pritchard and told her how I felt and she said it will get better. The dosages were increased but then I could not walk in a straight line and I felt that I was not in control of my body. The dosages were then decreased.

35. After 4 weeks, I had a test carried out, which confirmed that Hepatitis C had cleared; however I was advised to finish the course, which I completed.

Difficulties in accessing treatment

36. Due to taking Warfarin for my heart condition, I was limited to certain treatment drugs. However then I could not get access to the drugs that I required for treatment.

37. I therefore wrote to David Cameron and Jeremy Hunt on 22 May 2015 about access to treatment. I received a response on 10 June 2015 from Malcolm Jones, Ministerial Correspondence and Public Enquiries, Department of Health. I was simply informed about the progress of three new treatment drugs: Sofosbuvir, Simeprevir and Harvoni.

38. With no clear timescale and concerns over whether I would get the drugs, I informed my local MP, Neil Carmichael. On 17 July 2015, he wrote to Anthony Farnsworth, Directors of Commissioning Operations for South West, NHS England, about access to treatment.

39. Once the treatment drugs were given the go ahead, Gloucester Royal Hospital did not get the drugs. However the board at this Hospital agreed that as soon as Bristol received the drugs they would request it. The treatment drugs were requested and received - I started treatment in October 2015.

40. I would like to take this opportunity to highlight that our MP worked really hard to make sure that I got the treatment drugs. I know this because I looked at the Hepatitis C websites and some people are still waiting for the drugs - I was lucky to get it.

Treatment, medical and/or dental care for any other conditions

41. I did not feel any impact as a result of my infected status from medical professionals for any other conditions and they all know about it.

Private, family and social life

42. My daughter knows about the infection. I had to explain what would happen if I cut myself or if there was any blood contact between us. Initially she was worried that I would die and I had to reassure her quite a bit.

43. I think in some ways I trained myself to be a normal mum. I carried on for my daughter. I used to have days when I thought 'Why me?' I could have understood if I were a heavy drinker but to get on with life when I have done nothing was hard – I didn't expect to get a life killer. It is something that I should never have had. It does ruin your life. For example, when I go on holiday and when I go out, I am not able to drink wine – it has robbed me of certain circumstances.

44. I do believe that this virus contributed to the breakup of my marriage. I was feeling unwell, tired and I snapped at my ex-husband. He blamed me for not pulling my weight and went onto find someone else. I was about 45 years old at the time and I thought it was as a result of menopause, but looking back I realise that it was not.

45. My ex-husband is aware of my infection now - he has been tested and found to be clear of an infection.

46. My current Partner, my family and friends are also aware of the infection. I have never had a negative response. When I have explained it to them, they have been supportive, and particularly since it has been in the news. I have always been open about it; it is best to be open about it.

47. I have been pregnant four or five times but I miscarried - there may be a link between the miscarriages and the Hepatitis C. I was very sad and angry. Even now I am angry.

Stigma

48. My family and I have not experienced any negative impact from the stigma related to my diagnosis of Hepatitis C. I did tell the people at my Church and they were sympathetic. Even when I have purchased holiday insurance, the company would say that as the Hepatitis C has cleared, they do not need to know about it. Aside from those that need to know, I don't tell anybody else.

Education/Work/Financial effects

49. Hepatitis C did not impact my education.

50. However there has been an impact on my work and finances. I had to give up work due to being tired and depressed. I had nearly a year off from work but nobody knew why. During this time, my hands were purple in colour, I didn't have the energy and I could not even put on my uniform - I just sat at home in my dressing gown, which is unlike me.

51. I once worked in a charity shop but because it was too cold in the winter, I could not continue this work. How do you explain you can only work in the summer time and not the winter?

52. I cannot get Jobseeker's Allowance as I am not actively looking for work. I cannot get Personal Independent Payment as I am not outwardly disabled - I'm internally disabled. Apart from getting a Family Allowance, I get Child Tax Credit.

53. The benefits office are aware of my medical conditions but they said that it did not count. In my eyes there must be a loophole to be filled. I have a disabled blue badge but I cannot get anything. I do not know how I would manage without the money from Skipton, which I will discuss later in the statement.

Section 6. Treatment/Care/Support

54. I was not offered counselling or anything similar. I know that in my dark days, I was not thinking straight and it might have helped, but I am not sure what other people would know.

Section 7. Financial Assistance

55. I found out about the Skipton fund through my Hepatitis Nurse - I then went onto their website and requested the form.

56. After receiving the form, I completed my part and sent it to the Nurse. The Nurse then completed her part of the form and provided the medical information.

57. Around 2015, I received a stage 1 payment of £20,000.00 from the Skipton fund. The process took three or four months. I am not aware of any preconditions that were imposed on making the application or receiving payment.

58. My Hepatitis Nurse then said that I qualified for the stage 2 payment - we made the application in June 2015. We had to give photographs of my scars, which my mother photographed - it was very embarrassing for me. We were also required to give letters confirming all the medical conditions, surgery and blood transfusions proof - very hard to obtain.

59. In August 2015, I received the stage 2 payment of £50,000.00. The application process took around a couple of months. As far as I am aware, there were no preconditions imposed.

60. I am also in receipt of £1500.00 per month and a winter fuel payment of £500.00 from the England Infected Blood Support Scheme (EIBSS). These monthly payments were originally paid by the Skipton Fund and initially started at around £1200.00 per month, but gradually it increased with inflation.

61. My daughter also receives £200.00 per month from EIBSS. I have to apply annually for my daughter's support payment and it is unlikely that I will receive any more due to not being married to my Partner, even though my Partner does not contribute to my daughter or myself.

62. I do not know of any grants and did not receive any.

63. In terms of my observations on financial assistance, I believe that people living in Scotland and abroad received bigger payments than those people living in England. All the payments should be the same. Scotland should not have received separate payments as it is part of Great Britain - everyone had the same treatment and had the same disease, some have died from it. I believe everyone should have had bigger payments as it is life sentence.

64. I also found out that if someone is married, a quarter of the annual payment goes to the spouse. I am not married and we asked the Skipton fund that if this happened to me, would the payment go to my daughter. They said 'No'. I don't think that is fair because if a child is a dependant then they are no different from a spouse. Having said that, I think they are looking into it.

65. I also received a letter from Skipton saying that I can apply for income-related 'top-up' payments however I need to be in receipt of benefits. However when EIBSS took over, they said that is not the case anymore as benefits are not classed as income. I am therefore not in receipt of income-related 'top-up' payments from EIBSS.

Section 8. Other Issues

66. I believe I got Hepatitis in the 1970s and at the very latest I would have had it at the age of 12. It took until I was 51 years old to find out that I got it. I have carried the infection for at least the last 40 years. Prior to that, I was tired and the doctors kept telling me that it was due to thyroid or

menopause. I have had the symptoms since the 2000s and during this period I have had so many blood tests, why was it not found? I also had an HIV test done before the one carried out in 2014, and unless Hepatitis C was dormant in me, why was Hepatitis not found? Also, why don't Bristol Royal Hospital and Children's Hospitals keep records after 25 years?

67. As I know quite a few people who had transfusions, I told them about Hepatitis and they had never heard of it. I just feel that there are many more people who have had blood transfusions and contracted Hepatitis C like me.

68. There is another thing that irritates me. We are having this Inquiry and in my eyes, what is the benefit of why we are doing what we are? The main thing is that it came from the government and the NHS who paid prostitutes and prisoners to give blood - there must be someone there that must have the answers. As long as the answers come and something is done about it, that's what we really want. We will never really know how many people had the infection and died of it.

69. I feel quite let down to think that I have had to fight to stay alive after heart operations and then I then got something which I never should have had. Will I get cancer? Do I need a liver transplant? I ask myself these questions.

Statement of Truth

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

Signed GRO-C

Dated 28th march 2019.