Witness Name: David John Read
Statement No.: WITN00571 001
Dated: 07/12/18

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF DAVID JOHN READ

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 20 November 2018.

I, DAVID JOHN READ, will say as follows: -

Section 1. Introduction

1. My name is David John Read. My date of birth is GRO-C 1973 and my address is known to the Inquiry. I am married with 2 children and I work in the Civil Service, dealing with the regulation of the waste industry. My role involves setting the regulatory framework for the sector and ensuring the regulator has powers to deal with waste crimes such as illegal dumping. I am also a member of the Haemophilia Society.

2. I intend to speak about my experience of being infected with hepatitis C. In particular, the background and how I was infected, the nature of the hepatitis C illness and how it affected me, as well as the treatment I received and the impact it had on my family and I as a whole.

Section 2. How Infected

3. In GRO-C 1975, a few months before my second birthday I cut my lip quite badly. The bleeding did not stop properly and so I was referred to Yorkhill Children's Hospital in Glasgow where my family and I lived. After a few tests were carried out I was diagnosed with severe haemophilia A.

4. During that year, I attended the same hospital in Glasgow on 8 different occasions to receive treatment for my haemophilia condition. There were 3 injuries including an injured knee and another cut lip.

5. Around the same time my parents learned that my cousin on my mother's side also had haemophilia. We also wonder whether my mother's uncle had the condition too, so it appeared to be in the family.

6. In March 1976, my family moved to north Cheshire in the North West region of England and I was registered as a haemophilia patient at the Royal Manchester Children's Hospital, which we also referred to as 'Pendlebury'. I was under their care until the age of 20.

7. Unfortunately, I do not know when or indeed where I was infected with hepatitis C. I was treated with cryoprecipitate at the Royal Manchester Children's Hospital from 1976 until the middle of 1986, at which time I was 13 years old. I was under the care of Dr David IK Evans who was the haemophilia centre director.

8. During my visits to Pendlebury I remember that the cryoprecipitate came in blood bags, which were stored in a freezer. It needed to be defrosted before it could be administered to me and I understand it was derived from centrifuged blood plasma.

9. The cryoprecipitate was always administered via injection as opposed to a drip. I was on 'reactive treatment', which meant that I would only be

given cryoprecipitate if I suffered a bleed. (I didn't move on to prophylactic treatment with factor 8 until 2005).

10. In my early teenage years I seem to remember that I was given around 50-60 millilitres of cryoprecipitate on any given occasion. I received cryoprecipitate on a number of occasions whilst growing up.

11. For example, when my tooth fell out, when I sustained injuries to my knees or ankles, when my finger was trapped in a door whilst at school, if I had bad bruises to my muscles or bit my tongue or inner cheek. There was also one occasion when I had blood in my urine.

12. For the more severe incidents I required more cryoprecipitate than normal and as dosage is weight-based, as I got older, I also needed more cryoprecipitate to effectively treat a bleed.

13. On 29th August 1980, whilst on holiday at my grandparents' house, I suffered a bleed and received treatment at St. James' Hospital in Leeds. I was also treated once in Glasgow on 5th June 1981 at the Western Infirmary.

14. On 28th August 1983 whilst staying at my grandparents' home near Leeds I required treatment again at St. James' Hospital. I also received treatment at Raigmore Hospital in Inverness on 20th August 1984 whilst on holiday nearby.

15. Until the middle of 1986, when I turned 13, my treatment at Pendlebury was cryoprecipitate. In the instances above which were not treated at Pendlebury I do not recall whether I received cryoprecipitate or Factor 8 as a form of treatment, but I am pretty certain that on at least one occasion I was treated with Factor 8.

16. From mid-1986 at Pendlebury I received Factor 8 concentrate. Dr Evans at Pendlebury was confident that because it was BPL product there would be no infections present, as they were sourced from the United Kingdom.

17. Based on this my parents and I assume that I was infected through treatment received at one of the other locations. We trusted what Dr Evans told us, and had no reason to doubt him.

18. In 1991 I went to study at the University of Leicester. I registered with Leicester Royal Infirmary and had regular 6 monthly check-ups. In March 1993, I was invited for a specific blood test to test for any infections I might have contracted through use of blood products.

19. Then, in May 1993 I received the results at a regular check-up, which confirmed that I had the hepatitis C infection.

20. I have never taken any drugs intravenously and I do not have any tattoos or piercings and I had not had any sexual partners at the time so there wasn't any chance of contracting hepatitis C via other means.

21. I cannot recall whether the doctor in Leicester informed me of any precautions or gave any guidance after notifying me of my hepatitis C diagnosis.

22. However I believe the doctor would have given me the relevant information, as I do not imagine that I would have left the appointment without asking questions or feeling uninformed. Thus I have no reason to suspect that I wasn't given adequate information at the time.

23. I do not remember if I was also tested for HIV as well as hepatitis C. I think I already knew I was not infected because when I was in my mid-teens at school (possibly around 1987) I remember walking up the stairs to a class with my best friend. He knew I had haemophilia and he asked me if I had HIV. I remember saying no, so at that point I presume I had already been tested for HIV and the result was negative.

24. After my hepatitis C diagnosis I simply carried on with life as normal. As far as I can recall I did not receive any treatment for my haemophilia whilst

in Leicester. Before and indeed after my hepatitis C diagnosis I kept visiting Pendlebury as they still dealt with my haemophilia even after I turned 16.

25. I attended various appointments at Pendlebury outside my university term-times. I had been shown how to administer Factor 8 on my own in my mid to late teens. I remember one of the products was called 'Alpha' and it was a BPL product.

26. They also gave me boxes of Factor 8 blood products so I could take them to university with me to be used whenever I had a bleeding episode. I was under the care of the Royal Manchester Children' Hospital until 1993 when I turned 20 years old.

27. In December 1993 I registered with the haemophilia department at the Royal Liverpool Hospital where I was under the care of Dr Charlie Hay.

28. I wanted to get my university education out of the way before starting treatment for the hepatitis C. I completed an MA in the summer of 1995 and returned home to Cheshire.

29. I then started a 6 month course of Interferon from Liverpool in July 1995 and finished in January 1996 before I moved to London to start my career in the Civil Service.

30. Although the treatment was successful and the hepatitis C is cleared, I had a MRI scan in the late 1990s which showed that I still have scarring on my liver that is unlikely to disappear.

31. Dr Charlie Hay managed my care whilst I was in Liverpool until he left to run the centre at Manchester Royal Infirmary. At that point Dr Toh became the centre director at Liverpool.

32. As far as I can recall, I didn't meet with a hepatitis specialist whilst undergoing treatment. Dr Hay and Dr Toh were haemophilia doctors who also dealt with the infection.

33. My current doctor at Hammersmith Hospital (whom I have been under since I moved to London) is Dr Mike Laffan who is a professor of haematology and also has some expertise in hepatology.

Section 3. Other Infections

34. As far as I am aware I do not have any other infections other than hepatitis C.

35. However, I do have a clinical immunity to hepatitis B. Given the only way a person can have immunity to hepatitis B is by previously being exposed to it, presumably at some point I have been exposed to it but without that leading to a full-blown infection. Whether that was through a blood product or some other route I don't know.

Section 4. Consent

36. My parents recall that Dr Evans and his team at Pendlebury were always very open about the situation with infected blood. My parents were always able, and were encouraged, to ask any questions they had.

37. If they had heard anything on the news or had any concerns they were always able to just ring up and talk things through with Sister Shaw (the senior nurse in the centre) or Dr Evans.

38. Dr Evans was always gently adamant that he wouldn't give us blood that had not been sourced from the United Kingdom. There was no reason to doubt him. My parents were, and are, very relieved about that. They have

always been very thankful and felt very fortunate that I was treated at that hospital.

39. I don't believe I have ever been tested without my consent and if I was, it wouldn't have bothered me. I have given consent for my medical information to be used for hepatitis C and other research studies whilst at Hammersmith Hospital.

Section 5. Impact

Mental Impact of hepatitis C:

40. When I was diagnosed with hepatitis C I was in university and as far as I can recall it didn't have an emotional or mental impact on my life. I just got on with things as best I could. So it did not affect my private or social life and I have never felt that I couldn't talk to anyone about it.

41. I didn't actively tell people about my hepatitis C infection because it didn't ever come up as part of normal conversation. I wasn't ashamed to tell anyone but there was never any need to.

42. I haven't experienced any stigma whatsoever associated to having hepatitis C from anyone at all. My friends, family and in-laws are all relatively smart people and have open views of the world so I haven't had to hide anything from them for fear of stigmatisation.

Physical Impact of hepatitis C:

43. I do not recall having suffered any physical effects associated with having hepatitis C. Whilst growing up I do not believe I experienced grave tiredness or exhaustion and I have never suffered from brain-fog or confusion either.

44. Approximately 20 years ago I had an MRI scan and it showed some scarring on my liver, so that would be the main physical impact I know of.

45. I assume I still have cirrhosis of the liver and, as previously mentioned, the doctors believe it is unlikely that the cirrhosis will ever disappear.

46. I have always kept fit – I cycle regularly and walk a lot. I used to attend the gym and do circuit training but I haven't ever done contact sports, like football or rugby. Having hepatitis C has not stopped me from doing these things.

47. I was told at the time of the diagnosis not to consume heavy quantities of alcohol and although I drink alcohol, I am not a heavy drinker so this restriction does not have a huge impact on my life at all.

48. As a haemophiliac I cannot take aspirin or ibuprofen. I am aware that other pain killers, like codeine and paracetamol can affect the liver and I have received advice about that in the light of having contracted hepatitis C.

Impact of hepatitis C on Education/Occupation:

49. There were no effects on my education or my work that I can recall. I started hepatitis C treatment after I finished my university degree so it didn't have an effect on my educational pursuits.

50. I cleared hepatitis C before starting my career so I didn't feel the need to share it with my employer. However, I was always open about my ongoing haemophilia condition and I feel that working in the civil service has made things easier for me.

51. I have a very sympathetic employer that is supportive and understanding when it relates to doctor's appointments so I don't have any negative experiences in this regard.

Impact of hepatitis C infection on others:

52. As a genetic carrier for haemophilia, I think my mum always felt slightly responsible for my haemophilia condition and the subsequent hepatitis C infection.

53. I know she worries about me even to this day but she is very thankful that the hepatitis C is cleared now, as I think she would have felt much worse if I was still dealing with it.

54. My dad and I are very similar as he is very supportive and appeared to take the situation in his stride and got on with it whilst supporting my mum.

55. I have a younger sister and she was also at university when I was diagnosed and I know she worried about me too. So I know the hepatitis C definitely had an effect on my family.

56. At the time I was diagnosed I was in a long term relationship and we continued through university for another 7 years or so, but the hepatitis C didn't affect our relationship at all. We had already agreed not to have sexual contact for moral reasons so it didn't affect our life.

57. I do not believe the fact that I had hepatitis C in the past causes particular worry in my relationship with my wife now. My wife and I didn't meet until 2001/2002 she had originally trained as an occupational therapist and then worked in the pharmaceutical industry for a period, so that has always helped us, as she can understand things from a medical perspective.

Section 6. Treatment/Care/Support

58. The Royal Manchester Children's Hospital were very good to me and helpful throughout my time there.

59. In particular, my parents have told me on a number of occasions that Dr Evans, who is since deceased, was very determined that none of us, 'his boys' as he called us, should be given any blood or blood products that were sourced outside the United Kingdom.

60. The general atmosphere at the Royal Manchester Children's Hospital felt like a close-knit family. It was a really special environment and I feel I am amongst the lucky ones who received treatment under their care.

61. Dr Evans was the centre director for most of my time there, and Dr Stevens, who is also deceased, was his deputy. Dr Stevens took over as centre director in the last few years before I left. There was also Sister Alex Shaw who was the senior nurse. She was lovely and she treated us with the utmost care and kindness.

62. I kept in touch with Sister Shaw even after I stopped being a patient at the Royal Manchester Children's Hospital. When she died in the mid-2000's, I cried for a long time. I guess she was a bit of a mother figure to me in some way.

63. Dr Evans was very careful to protect his young patients from blood products that didn't originally come from the United Kingdom. When I moved on to Factor 8 in 1986, it was sourced within the UK. The treatment I had was from Blood Products Laboratory (BPL) and I remember the labels on the products. This was reassuring for my parents and me.

64. I therefore do not believe I was infected at Royal Manchester Children's Hospital.

65. After I was diagnosed with hepatitis C in 1993 I decided to wait until I had completed my university degree before I began treatment. I do not remember if I attended any specific appointments relating to it in the intervening period.

Mental Effects of Treatment

66. As previously mentioned, I began a 6 month course of Interferon which was dispensed to me from the Royal Liverpool Hospital. The course of treatment started in July 1995 and ended in January 1996.

67. I was working in a temporary administrative role in Cheshire at the time and as I was living at home with my parents I didn't have to worry about looking after myself such as cooking and cleaning etc., so it was an easy period during which to go through the treatment.

68. Interferon had to be injected subcutaneously in my abdominal area. This really was difficult. A bit like injecting Factor 8 intravenously in my arm, it was very emotionally and mentally exhausting.

69. The Interferon had to be taken 3 times a week so I would inject it shortly after returning home from work in the evenings. It was horrible and I hated doing it.

Physical Effects of Treatment

70. I do not wholly remember how much of an impact the Interferon treatment had on my life. However I was living at home with my parents at that time and they can recall that it made me very tired.

71. Based on my parents' account, I would go upstairs to my bedroom when I got home from work and inject myself with the Interferon and then have something to eat and fall asleep for around 12 hours or so.

72. I think they noticed the impact the Interferon had on me because normally I was quite physically active.

73. However my parents have said that the Interferon left me feeling tired and groggy – the standard side-effects of slight flu-like symptoms. I cannot

personally remember any of this so I have had to rely on what my parents have told me.

74. A couple of months into the Interferon treatment the doctors said that I seemed to be responding well and the knowledge of that motivated me to continue taking it, despite the unpleasant injection. I'm pretty resilient, which really helped me get through it I believe.

75. To the best of my knowledge I don't believe I suffered any adverse effects or lasting effects from the Interferon treatment.

76. It didn't affect dental care as far as I can recall and my teeth are very healthy so I haven't had to make frequent trips to the dentist. I didn't receive any bad treatment from any medical professional as far as I am aware as a result of the treatment or infection.

Counselling

77. I don't think I was offered counselling when I was diagnosed at Leicester but in all honesty, I cannot actually remember that period of time very well, so it is also possible that I may have been offered it.

78. When I started treatment for hepatitis C in Liverpool there was support from a psychologist if I needed it. I can remember speaking to her on one occasion and she offered me counselling and support, but I said I didn't need it.

79. I am currently registered at Hammersmith Hospital where I receive check-ups every 6 months to monitor my haemophilia condition.

80. They also conduct regular blood tests and they have told me that even though I am clear of the hepatitis C infection, there still remains a marker in my blood that shows that I had hepatitis C but the infection is no longer active.

81. Dr Laffan and the team at Hammersmith have always been clear that if I, or indeed my wife, need any support or guidance (not just about hepatitis C) they would be happy to talk to us either individually or together.

82. One of the things that I love about haemophilia centres, at least in my experience, is they always include the family and they realise my condition doesn't just affect me, but it has an impact on my family too and they equally need support.

83. I have always felt that if I wanted more medical input I could always ask for it. I also do not believe that any doctors have been too proud to bring in other specialists if they thought they could help.

84. I don't believe any medical professional made it difficult for me to access care or information and I have nothing but good things to say about how I have been treated by them.

Section 7. Financial Assistance

85. I learned about the Skipton Fund when it was originally introduced both in the media, through the Haemophilia Society and through the haemophilia centre at Hammersmith Hospital.

86. I applied for the lump sum funding in 2007 and received £20,000. Two years ago the new monthly payments were introduced as well as the winter fuel allowance, and I am eligible for, and so receive, those. The process was straightforward and Dr Laffan signed the forms to confirm my eligibility.

87. There were no difficult preconditions imposed by the Skipton Fund, it was a straightforward process. It was potentially a bit confusing that there were different funds set up for different infections.

88. It would have been an added complication to have to apply to different funds if I had been infected with other viruses.

89. To be honest I wouldn't say I particularly needed the money given to me at the time. However, I was eligible so it seemed daft not to apply for it.

90. Also of course, as my liver still has signs of cirrhosis, I knew that the money may be useful many years down the line, so there was some practical reason for applying as well.

Section 8. Other Issues

91. Even though I was infected through use of contaminated blood products I don't feel like a victim.

92. My life hasn't been screwed up by this and I have been lucky to have received brilliant care from doctors and nurses who have been absolutely wonderful and for whom I have a great deal of affection and respect.

93. I completely understand that other individuals have not had the same treatment and have suffered greatly, but I do think it is important to 'shout up' a bit for the NHS, as I believe they did the best they could for me at the time.

94. I haven't been involved in any campaigning or any process of litigation. I am also happy for any member of the Inquiry to obtain my medical records. I will be interested to see what the outcome of the Inquiry is.

Statement of Truth

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

Signed GRO-C

Dated 24/3/19