

Witness Name: James Robert Pepperell

Statement No: WITN1008001

Exhibits: WITN1008002 to WITN1008013

Dated: October 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF JAMES ROBERT PEPPERELL

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I, James Robert Pepperell, will say as follows:-

#### Section 1. Introduction

1. My name is James Pepperell. I live at GRO-C, Hampshire GRO-C I was born on the GRO-C 1941.
2. I am retired. I have two sons (aged 50 and 48) from my first marriage. I met my wife Carole in 1997 and we got married in 2001. Like me, Carole is retired.
3. I was infected with Hepatitis C Virus as a result of receiving contaminated blood products (Factor IX) in 1979 and/or 1983. I received treatment for the virus in 1998 and 2003, following which I thankfully cleared the virus.
4. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are referred to in this statement.

#### Section 2. How infected

5. I am the eldest of four siblings. I inherited Haemophilia B (also known as Christmas Disease), a Factor IX deficiency, from my mother. I was the only sibling affected; my two brothers and sister do not have haemophilia.
6. I have Haemophilia type B, classed as mild. I was told my clotting factor is around 20-25%. Due to the relative mildness of my condition it meant that I was able to live a largely normal life in childhood and adolescence. From time to time I suffered abnormal bleeding particularly after teeth extraction and from haematomas following football or cricket injuries.
7. I was diagnosed with Christmas disease in 1962 at the Radcliffe Hospital in Oxford following a major haematoma. In 1962 there was no treatment at all other than bed rest and blood injections. They couldn't stop my bleeding if I had an accident. Then the miracle cure for haemophiliacs came out in the 70s in the form of Factor XIII and Factor IX blood products. By this time I was living in GRO-C near GRO-C.
8. As a Haemophilia B sufferer, I was issued with a special medical card from Royal Bournemouth Hospital in January 1979 which stated my condition, in case I was in a road accident or anything. I have attached a copy of this card to my statement, marked WITN1008002.
9. I received Factor IX concentrate intravenously in 1979 and 1983.
10. In 1979 I was treated for haemorrhoids at Salisbury General Hospital. I was referred to the haematology centre in the hospital to see Dr Pinkerton, the Chief Haematologist at the time. I was provided with Factor IX by the hospital which I took home with me. I was asked to telephone my GP so that he could administer the Factor IX.
11. My GP, Dr Ansell, came round and gave me the first injection intravenously. He had never given it before and wasn't aware of how to inject it, I remember he had to call the haematology centre for advice. After this I attended the hospital

daily for around 3 or 4 days and was treated at the hospital with Factor IX blood products.

12. I didn't receive any more Factor IX until I had some wisdom teeth removed in 1983. I was advised to have this done in hospital due to my haemophilia. I was treated at Odstock Hospital in Salisbury. The hospital injected me with Factor IX prior to the surgical procedure to bring my clotting levels to normal. I had the teeth removed and stayed in hospital. I was given one more injection of Factor IX before I left.
13. I did not receive any more blood products until 1997. Most haemophiliacs require daily injections. However I had no more than 6 before 1997.
14. I was infected with Hepatitis C as a result of receiving contaminated blood products. I was infected in 1979 or 1983 as these were the only occasions I was treated with Factor IX before 1997.
15. I was never told that there was a risk that I could receive an infection from being treated with Factor IX.
16. I was told that I had Hepatitis C in April or May 1998 by Dr Winwood, Consultant Gastroenterologist at the Royal Bournemouth Hospital. I had been feeling increasingly unwell and unusually tired for a considerable period of time, probably 5 or 6 years. I initially put this fatigue down to my lifestyle circumstances. I was in my mid 50s and I held a senior position as operations director of a company. My job involved lots of travelling, commuting and meetings. I was also going through a very lengthy divorce and financial settlement. I had responsibilities towards my sons who were in university and drama school. I initially assumed that my symptoms were related to all of the stress I was under. My symptoms did not improve and I ended up going to my doctor who referred me to the Royal Bournemouth Hospital for tests.
17. After he told me about my infection, Dr Winwood asked if I had taken drugs or anything of the nature which I had never done. He then looked at my history of injections and honed in on the fact I was a haemophiliac and had received blood

products. They started to heat treat blood in the late 80s so Dr Winwood could be quite specific in my case as to when I would have been infected.

18. Dr Winwood told me that I would need to undergo further tests to see if I had been infected with HIV and that he would ask Dr Worsley, Consultant Haematologist to take care of this.
19. I was very shocked by the news that I had Hepatitis C. And very worried that I may also have HIV. The further blood tests were taken by Dr Worsley and after an agonising 2 week wait I was told the tests results were negative for HIV.
20. I have attached to this statement marked WITN1008003 blood test results dated 16 April 1998 and 13 May 1999 which confirm that I tested positive for Hepatitis C and that I was HCV genotype 1a.
21. I also attach marked WITN1008004 the following:
  - a. letters dated 10 June 1998 and 11 June 1998 which state that I almost certainly acquired my Hepatitis C infection from factor 9 transfusions;
  - b. letter dated 17 June 1998 confirming that my blood was negative for HIV.
22. I don't have any problems with the way the information was communicated to me. I was however upset that they hadn't tested me for HIV at the same time they tested me for Hepatitis C. They must have known what they were looking for. HIV was a death sentence in those days so the possibility that I might also have contracted HIV was really worrying.
23. I had had blood tests previously but they were never in relation to Hepatitis C. Nothing had ever been said to me about the possibility of having any infections as a result of being treated with Factor IX. I was never asked to go for any tests or anything. Even though I was registered as a haemophiliac and had been given blood products in the period where they knew I was at risk. If I hadn't gone to see my doctor I wouldn't have found out about my infection.
24. I was told by Dr Winwood that the long term effects of Hepatitis C could lead to cirrhosis of the liver and that I was 5 times more likely to get liver cancer.

25. Dr Winwood and Dr Worsley told me that there was a risk of me transmitting the virus to others. I had been undiagnosed for around 20 years so I was worried about the damage that could have been caused in that period. I could have shared toothbrushes or razors in that time so I was worried I could have infected my family.
26. Other than this I wasn't really told an awful lot. The information wasn't really adequate. They were in the infancy of dealing with people in my position at the time and I don't know how much more information they could have given me.
27. I do believe the information provided to me should have been given earlier. I should have been on a list as I was a high risk patient due to the fact I am a haemophiliac and they were aware of the issue with contaminated blood. I had an official medical card so it should have been flagged up and I should have had a letter or meeting in the 80s explaining I was a high risk patient.
28. When I asked questions about this I was told Hepatitis C only came to the fore in the mid to late 80s so there was no action taken before this. But in my case they didn't approach me at all. I went to see my doctor in 1998 because I had been unwell for so long.
29. I believe my liver has been permanently damaged and although the virus is no longer detectable I am still at an increased risk as a result of my infection with contaminated blood.

### **Section 3. Other Infections**

30. As far as I am aware, I have not received any infections other than Hepatitis C.
31. In 2004 I received letters from the Department of Health saying there was a possibility that I had been exposed to vCJD (Mad Cow Disease). As far as I know they can only find out if you have it after you have died so I will never know. The CJD documents are supplied to support this statement marked WITN1008005.

32. I have attached to this statement marked WITN1008006 a letter from the Royal Bournemouth Hospital dated 20 September 2004 and a letter and enclosed vCJD Fact Sheet from the Haemophilia Society dated 21 September 2004. Both of these letters indicate that I may be at risk of having contracted vCJD as I was treated with Factor IX during the relevant period.

#### **Section 4. Consent**

33. Although I was aware I was undergoing tests in relation to issues with my liver, I was never told explicitly that I was being tested for Hepatitis C. It is therefore possible that I was tested without my consent. When I saw Dr Worsely after having been told I have Hepatitis C she informed me she hadn't tested me for HIV as I hadn't given consent which seemed strange as they hadn't acquired my consent to test for Hepatitis C either.

34. I was not made aware that there was a risk that I could receive an infection from being treated with Factor IX. Other than this, I do not believe I was treated or tested without being given adequate or full information.

35. I do not know if I was ever tested for the purposes of research.

36. I was treated for Hepatitis C with Ribavirin and Interferon as part of clinical trials. I attach to this statement marked WITN1008007 a letter dated 22 June 1998 and an undated consent form signed by me which confirms this.

#### **Section 5. Impact of the Infection**

37. My initial feeling when I was told of my Hepatitis C infection was complete shock. How on earth had I coped with this virus without being aware of it for maybe 20 years?

38. Following consultations with Dr Worsley and Dr Winwood, I understood that my liver had been damaged by the virus and that I was at an increased risk of

developing cirrhosis and liver cancer. I was also made aware that I could have hypertension as a result of Hepatitis C.

39. I felt as if a large cloud had descended on me. I was under extreme stress mentally as a result of my diagnosis. The two week period while I waited to find out if I also had HIV was agonising and extremely stressful.

40. As I was told more about the implications of liver disease arising from Hepatitis C and the possibility that others close to me might be infected I was very upset. I was 3 months into a new relationship with my now wife and I was distressed about the situation going forward. Thankfully she stuck with me. My wife was a nurse and she administered my Hepatitis C treatment.

41. I was extremely concerned that I might have infected my family. This resulted in me putting additional stress on my immediate family. My sons were grown up by this time and had left home, but I was conscious that I had lived with this virus for some 20 years at this point and that there was a possibility that I could have infected them or my ex wife.

42. Dr Winwood told me that Hepatitis C was a new liver virus and that I would require a course of anti viral treatment in order to kill the virus. I gathered I would have to wait for treatment to start but I wasn't sure why.

43. I underwent two separate treatments for Hepatitis C

44. The first was in September of 1998. It was combination therapy that consisted of Interferon, in the form of injection, approximately four times a week and Ribavirin, in the form of tablets, which I took daily. The treatment of Interferon and Ribaviron lasted for around 4-6 months.

45. The mental and physical effects of the treatments on me were horrible. I suffered from extreme fatigue, nausea, weight loss, nasal congestion, dandruff, depression, a loss of confidence and low morale. It exacerbated my diverticulitis. I could not live a normal life. I had to scale my work back and I was put on anti-depressants because of the effects the treatment had on my

mental health. Side effects of the treatment have been exhibited as per WITN1008008.

46. At the time I was taken off the treatment, I had not cleared the Hepatitis C virus but I had partially responded to the treatment. Liver scans showed that my ALT's had reduced substantially and my liver inflammation was going down. I was surprised when the treatment was stopped at this point, and believe the treatment was halted prematurely.
47. I believe I was taken off the first treatment too early due to a lack of funding. I was told that because I hadn't cleared the Hepatitis C virus I would have to wait for new medication to be introduced before I could receive any more treatment.
48. When I enquired about the recommencement of treatment, I was told that I would be in a 'later tranche' for treatment. I took this to mean that they were waiting for funding rather than the evolution of new drugs.
49. I attach to this statement marked WITN1008009 copies of letters dated 29 September 1998, 26 October 1998, 6 January 1999 and 8 September 1999. The letters confirm that I started treatment for Hepatitis C with a combination therapy of Interferon Alpha and Ribavirin in September 1998 and that treatment was stopped in September 1999. The letters also confirm some of the side effects I experienced during treatment such as diarrhoea, tiredness, malaise and depression for which I was treated with Prozac.
50. My second round of treatment started in 2003, 3 years after I had been taken off the previous treatment. It lasted for around 9 months. Again it was combination therapy that required injections (PEGylated Interferon) and tablets (Ribavirin). During my second course of treatment I attended clinic regularly for ALT readings and liver scans.
51. By the time I was on the second treatment I had taken early retirement at age 59. As with the first treatment, the side effects were horrible. The side effects were so bad that I wanted to stop the treatment early, 2 months before the



course had finished. I was encouraged by my wife and doctor to complete the treatment because the results so far had been very good.

52. The second treatment was, thankfully, successful in clearing the Hepatitis C infection.

53. I attach to this statement marked WITN1008010 a copy of a letter dated 5 February 2003 confirming that I would be treated with PEGylated Interferon and Ribavirin, and a copy of a letter dated 19 January 2004 confirming that my treatment was successful.

54. I also attach to this statement marked WITN1008011 copies of letters dated 26 February 2003, 5 August 2003, 25 September 2003, 10 November 2003 and 29 December 2003 which refer to the side effects I experienced during my treatment, such as severe fatigue, nausea, loss of appetite, insomnia, back pain, depression, abdominal bloating, trapped wind, diarrhea and dry skin.

55. I have found some difficulty in receiving treatment I needed because of my Hepatitis C infection. For example it was really difficult to get dental work done. Dentists would always put me to the back of the list. I am no longer under the care of the NHS as it was too difficult, I have since gone private.

56. I have attached to this statement marked WITN1008012 a copy of a letter dated 5 June 2001 that my GP wrote to the hospital after I complained to him that my dental hygienist had refused to treat me; and a copy of the response received from the hospital dated 23 July 2001.

57. The damage has been done to my liver. My last liver scan was good but I haven't been offered one for around 8-10 years so I am not sure of its current state.

58. My children were grown up and had left home by the time we found out about my infection. They were concerned about my health rather than theirs even though I told them they could have possibly been infected through me.

59. My partner (who is now my wife) and I were 3 months into a new relationship. She was shocked at the time and I was really distressed about what our future would hold. We have a very strong relationship and she administered my treatment. I believe I've come out on the right side of this, I feel fortunate compared to other people I hear about who were, like me, infected through contaminated blood.
60. During the period before I cleared Hepatitis C, my wife and I lived with the burden and the fear that the virus could be transmitted to her.
61. I was worried about the possible effects of the stigma around the infection. I had to tell my work about my condition. I had always lived a normal life and people didn't know I was a haemophiliac. I did not want to be viewed as a drug addict and so when I told people about my infection I also told them how I had sustained it.
62. My biggest concerns though were that I may have infected my ex wife, children and my new wife and that I may have sustained irreversible damage to my liver.
63. If I hadn't been infected with contaminated blood I wouldn't have had the issues I have had with my health and I wouldn't have had to retire so early.
64. It is difficult to quantify the financial effect that my infection has had on me. The early retirement had an impact on my final salary pension. Luckily I was a director and had good incentive and benefits; I also received severance pay. I was ill until 2004 and therefore in the first four years of my retirement I was unable to undertake any arduous employment.

#### **Section 6. Treatment/care/support**

65. I am still not sure why I initially had to wait 3 months for the initial treatment. I believe I should have been given the treatment immediately for the benefit of my health.
66. I also believe that the first treatment was halted prematurely and that if it had continued I may not have needed to be treated a second time.

67. I was never offered any form of counselling or psychological support. When I was on treatment for Hepatitis C I was very depressed. I was on antidepressants as a result. Fortunately I have not had to take them since completing Hepatitis C treatment.

## **Section 7. Financial Assistance**

68. I received £20,000 from the Skipton Fund in 2004. It was explained to me that this was an ex-gratia payment.

69. As far as I remember the process was fairly straight forward. I was guided by the Haemophilia Society in relation to what I was entitled to.

70. Around 3 or 4 years ago I started receiving money from the England Infected Blood Support Scheme (EIBSS). I didn't apply for it, I just started receiving it. I understand that EIBSS is a government agency connected to the Skipton Fund and Macfarlane Trust. I am on the minimum payment of around £3,000 or £4,000 a year.

71. On the first day of the Public Inquiry the government announced increased payments to those who had been infected. I received notification from Business Services Authority (EIBSS) on 3rd May 2017 that my future payments would no longer be means tested and would increase to £18,458 from 1st April 2019.

72. I have not received any further financial support.

73. Fortunately I am in quite a good financial position. However I am worried that if something does happen to me there will be a significant impact on my family. I have spoken to my wife about this and made her aware that should my liver worsen to stage 2 she could receive future financial support.

## **Section 8. Other Issues**

74. I have not been involved any litigation regarding contaminated blood.

75. In the early 2000s I canvassed my local MP in order to try and help those who had been infected or affected in relation to the contaminated blood scandal. More information was coming out and I was concerned, I wanted to help people who had been affected and believed MPs should support the cause. Unfortunately I was not able to receive any help. I have enclosed copies of correspondence with my MP under exhibit WITN1008013.

76. I believe there are questions to be answered. I only found out I had been infected with Hepatitis C because I went to my doctor. I believe that as a haemophiliac registered in 1979 and again in 1983 with documentary evidence to support, I should have been flagged up as a high priority risk and advised by the authorities that I was at risk of infection, particularly as it became clear in the mid 1980s that an epidemic of HIV / HCV was evolving among haemophiliacs.

77. My first treatment was stopped early and I believe I would have benefited from it continuing. I therefore question whether there were monetary constraints in relation to being offered treatment for Hepatitis C.

### **Anonymity**

78. I do not wish to remain anonymous.

79. I am willing to provide oral evidence to the inquiry.

### **Statement of Truth**

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

Signed

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GRO-C

Dated ..... 23<sup>rd</sup> October 2019 .....