Witness Name: Graham Knight
Statement No.:WITN0216001
Exhibits: WITN0216002 - 07
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRAHAM KNIGHT

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5 November 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Graham Knight, will say as follows: -

Introduction

1. My name is Graham Knight. My date of birth and address are known to the Inquiry. I am an ex Liberal Democrat councillor and live in GRO-C West Sussex with Sue, my wife. I have lived in GRO-C since 1963 and have been married to Sue for 24 years; but we have been together for just over 25 years.

2. I intend to speak about my contraction of Hepatitis C following administration of infected blood products. In particular I wish to cover the nature of my illness, how the illness has affected me, the treatment I received and the impact all of this has had, upon my family and myself.

3. I confirm that I am not legally represented and that I am happy for the Inquiry team to take my statement.

4. I am a member of the Haemophilia Society but have informed them that I am not participating in their part of the Inquiry and not participating in any of their actions.

How infected

5. I suffer from Von Willebrand's (VW) disease which is a congenital bleeding disorder. I was originally just diagnosed as having haemophilia, (in those days they didn't have the a and b categories). However in the 1990s my condition was termed VW after the medical community had come up with this term. I believe at this point that clinicians also came up with the Haemophilia A and B categories (**WITN0216002**).

6. VW led to me having joint and muscular bleeds on a number of occasions when I was growing up. It also meant that I had to be hospitalised when I had dental extractions.

7. Around the age of 10, I recall having teeth removed outside of hospital and I bled for about three weeks. Since then I have always gone to the hospital when I have had dental problems. I had to stop doing things to stop generating blood pressure that might make the bleeding continue. The wound was not packed and I just had to wait for the bleeding to stop.

8. Due to the risk of blood going into my joints I tended to avoid sports when I was growing up. Later on in my childhood however, at the age of 14, I did take up judo but this was stopped when I was 17and the doctor found out.

9. My condition causes me to bruise very easily. I recall one incident in which I was lifted up by my friend during my judo class and then dropped by accident. I landed on my knee and had an internal bleed. I ended up at hospital with a knee like a football.

10. The doctor drained the blood and advised me not to continue judo. I am unable to recall for sure whether I was given any blood products as part of my treatment but I hope this information will be in my medical records. I remember some form of medication being given intravenously. The doctor wanted me kept in the hospital for a few days, but I said I was fine and went home and just rested my knees for a few days.

11. I also had a cyst removal operation in 2018 and the report after the operation came back suggesting I had severe Haemophilia A. I wish to clarify this diagnosis, as I have not previously been informed of this. I have now received assurances from my Haemophilia Consultant, that this is a typographical error and he is undertaking to have the report altered to remove the Haemophilia A comment.

12. As I understand it, the level of clotting factor in the blood stays constant during life so I believe there has been an error in my records somewhere, perhaps via a “cut and paste job”, as I think I would have been informed earlier, if I had severe Haemophilia A. I have been having biannual ultrasound check-ups and blood screening tests, since early 2004 and none of these indicate I have Haemophilia A.

13. On 9 or 10 February 1983, I received 7 units of Factor 8 blood product during a bilateral vasectomy operation carried out at Guy’s Hospital (as shown in a clinical letter dated 2 March 1983 from Dr Dick to Dr Davies – **WITN0216003**). There is mention of a vasectomy recorded on a note from my GP dated 4 February 1983, **(WITN0216004).**

14. I was conscious when the blood product was being administered intravenously. It was an entirely a voluntary procedure. I saw red liquid coming down a tube, which went straight into a cannula. I am aware that this was also

how my anaesthetic was administered. I had a general anaesthetic for the operation and may have been given Factor 8 whilst under the knife but I was not conscious at this point.

15. Clinicians at the specialist haemophiliac unit at St Thomas' have subsequently informed me that Factor 8 has limited therapeutic value, and that I should have been given Factor 9 and platelets to treat my deficiency.

16. I was kept in overnight for 3-4 days after the operation to ensure that the bleeding had stopped and was under control.

17. Later the same year, in November I had an urgent appendectomy; again this procedure was carried out at Guys Hospital. I was kept in 7-10 days for this operation.

18. As part of the procedure I was given a blood transfusion and blood products. A clinical letter from J A Maynard Consultant Surgeon to Dr Davis (my GP) confirms that the appendectomy was performed "under Factor VIII cover" (**WITN0216005**).

19. I am unsure exactly how many units of blood I was given as part of my appendectomy. My GP records don't indicate how much was administered. I have however applied for my records from Guys during this period.

20. When I was later diagnosed as Hepatitis C positive, I was informed that the infected batch had been traced and it was the one I was given as part of my appendectomy. It is possible however that I was infected before this point. The information was given to me verbally, as part of the conversation when I was diagnosed at St Thomas', Sue was there as well, so she will be able to verify this. It may be in my clinical notes, but I've not requested these, but will do so.

21. The nurse who admitted me, was aware of the HIV infection and I recall making a joke that if appendicitis didn't get me, HIV would. The joke was like a flat pancake and the nurse clearly didn't share my sense of humour. Following admission to the ward, I was examined by a surgical registrar and then by a surgical consultant, who confirmed I had appendicitis. His diagnosis indicated that it was advanced, and they operated within 2-3 hours of my admission. Again I saw tubes and a bag with blood in it before I went under.

22. I was interviewed after the operation by a lady consultant, whose name I cannot remember. This lady was the head of Guys Haematology team at the time.

23. I had bloods taken as the consultant explained that there was a slight risk of HIV infection. This news was devastating to me at the time, especially as I was a young father, still struggling to make up the earnings I had lost whilst being off work for six weeks post op.

24. I returned to her clinic a week later and was informed that I was HIV negative.

25. I was informed that I needed to be monitored as there might be something else. I was not told what this "something" was, except that it was a different "milder virus". I was told there was an even lower risk of me contracting this additional infection. Doctors at the time didn't know about NonA NonB Hepatitis.

26. In the end I didn't receive any further monitoring from the consultant or her team.

27. I did ask Dr GRO-D, who replaced the lady consultant as clinical lead, about this other "milder" virus but I never got an answer other than that he was not aware of anything. I didn't pursue it any further as I believed the Hospital would have kept me informed if anything else needed checking.

28. I was therefore kept in the dark until I was confirmed as Hepatitis C positive in November 2003 by my GP, at the time. This was then confirmed by St Thomas Haemophilia unit in January 2004.

29. The only other treatment I received during the period the Inquiry is focusing on, was dental work, as part of which I was given DDAVP. This is a coagulant to glue my platelets together. I was not given any other transfusions or blood products to my knowledge.

30. I never kept Factor 8 in the home and did not inject it regularly. It was given to me in cases of injury or as part of operations. I stock tranexamic acid in my home for emergencies.

31. I will now set out the circumstances in which I discovered I was Hepatitis C positive.

32. I became unwell around 1997. I went to see my GP who ordered regular blood tests and concluded I was drinking too heavily. I was informed that this, combined with the stress of owning and running my own small engineering business, was damaging my liver.

33. My blood test results indicated that my liver was under stress due to the enzyme levels.

34. I stopped drinking straight away and my liver did recover slightly, but then started to deteriorate again. I had stopped drinking alcohol completely when I first had the GP advice and have never touched any since; even to the extent of refusing food cooked with any alcoholic ingredients.

35. I continued to have deteriorating health and the blood tests (which were, I was told, full screening tests) continued to show liver damage and I was still being told to stop drinking!

36. Finally in November 2003 I insisted I was referred back to Guy's. Before my GP, Dr GRO-D referred me, however, he suddenly insisted I have a blood test for Hepatitis C. I'd never heard of Hepatitis C at that time.

37. I was informed over the phone 3 days after my blood test that I needed to come in for an appointment. I attended the surgery for my appointment.

38. I remember Dr GRO-D telling me "the results of the tests are positive and you have Hepatitis C". Dr GRO-D then said, "I think you need referring up to Guys". I was in a bit of a shock at the time so I may have been told more but do not recall anything else

39. The Trust had by that time rearranged where Haemophilia patients were treated, and I was first introduced to the Haemophilia Reference Centre at St Thomas'.

40. Following retesting at the Centre it was confirmed I had Hepatitis C and it was at this point that the infected batch was traced.

41. I made another appointment to see my GP and asked why I hadn't been tested before. I was informed that this was because my GP was not aware that I had had blood products.

42. A pre-treatment plan was made with the Centre's Hepatitis C team of specialists and a "key nurse" was allocated to me to provide information and to deal with any problems quickly.

43. The most difficult part for me was informing my former wife of her potential to have contracted Hepatitis C from me during our marriage. This had ended several years earlier quite acrimoniously. I never heard back from her.

44. Kate, my key nurse at St Thomas' provided information about the risks of infecting others during one of my outpatient appointments. I was told about using condoms and advised not to share toothbrushes. Kate also checked that I don't inject drugs intravenously.

45. My main concern was my children and grandchildren. I have always suffered from nosebleeds, which is part of the VW. I recommended to my children that they get tested. I could not guarantee that they had not touched my blood at any stage.

46. I asked about the risk of passing the infection on to my grandchildren and was told that it will be fine. I was informed that there would be a risk if I bled and anyone touched that blood with an open wound. I asked about sharing towels and was told that that would be fine. I was told that unless I had sex with another person or exchanged blood then there would be no risk.

47. I believe that I was given adequate information about my infection by the staff at St Thomas', but not from my GP.

48. I believe that my GP should have arranged for me to be tested at an earlier date. I feel that my GP has completely failed in the duty of care he owes his

patients. As my GP was aware I had a bleeding disorder, he should have checked to see if I had been given any blood products in the past.

49. I had a series of blood tests over a five-year period, none of which were checked for Hepatitis C. This is despite the fact that my symptoms were classic indicators of Hepatitis C infection.

50. When I returned to see my GP and ask why I hadn't been tested earlier, I also asked to see my medical records. It took me less than 30 seconds to find the letter relating to the vasectomy operation, which confirmed that I had received 7 units of Factor 8.

51. I thanked the doctor for his help and left the surgery. I don't think I ever saw him again, despite him remaining my GP for a few more years. I was always passed on to a colleague.

52. I confirm that I have never had any piercings or tattoos; nor have I been sexually promiscuous or engaged in intravenous drug use.

Other Infections

53. As far as I am aware I was infected with Hepatitis C only, from infected blood/blood products.

Consent

54. I don't think that I was treated or tested without my knowledge.

55. I also don't think I was ever treated or tested without my consent. Doctors have been very open about things and I believe that generally I was given adequate information about my treatment. I do recall however that during my appendectomy I was just asked to sign a consent form as a formality and no details of the treatment I would be given, including blood or blood products, were discussed with me beforehand.

56. On a couple of occasions I was asked if a researcher could review my file. One of these was using my medical information as part of his PhD. I recall signing a form before my medical data was used. I can't remember when this was but it was after my diagnosis with Hepatitis C.

Impact

57. Prior to my diagnosis in 2003 I started to feel unwell: this was nothing specific at first, just a feeling of not being fully on my game.

58. I was getting mental fogs and a severe debilitating fatigue, which led to my business getting away from me. In or around 1997 I felt very ill and my wife insisted that I go to see my GP.

59. I describe myself as 'beggared' at work and was falling asleep at my desk. I would be fine and would get into work at 6/6.30 as this was the most productive time for me. Then, by about mid-morning I would start to feel weary and then come the afternoon I would be falling asleep at my desk. I had staff coming in to my office to wake me up as something needed doing. This was causing stress in itself and the GP continued to ask me to stop drinking even though I wasn't.

60. I have supplied a letter to the inquiry, it is to Dr GRO-D dated 19 January 2004 and among other issues, it shows a reference to my 'history of alcohol excess', which as I say, I did not have. (**WITN0216006**)

61. When my infection with Hepatitis C was eventually diagnosed and confirmed in late 2003, I was very ill. I was still just about holding a job down, but I knew I was only just doing enough to get by.

62. I was exhausted all the time, feeling nauseous constantly and in a high level of total muscular pain and discomfort. I was briefed by St Thomas' that normal pain relief was off the menu as aspirin, paracetamol and ibuprofen were causing further damage to my liver, which was by that time already moderately to severely cirrhotic.

63. I suffered from mental fogs, which are very frustrating to say the least. I used to have instant recall, but now find there are gaps in my memory. My memory does come back eventually, but generally after the moment has passed. My family are aware of this and don't make an issue of it. My wife takes most of the stress out of it as she has good recall.

64. It was going to take the St Thomas' team some months to get me fit enough to undergo my treatment. This treatment was going to consist of a combined Interferon injection and Ribavirin tablet treatment.

65. Prior to undergoing the treatment, I was warned that there was only a 30%-40% chance of eradicating the virus. I was also warned that I could lose around 28lbs (12-13 kgs) in weight.

66. I had to push the doctors to commence treatment as they were reluctant to start until I was fully well. They wanted a belt and braces approach, which would mean that the treatment had a minimum risk to my health. However I told the hospital: 'I want to start this'. I feel it was completely irrational now looking back, to push for the treatment to start earlier. But at the time, 'I wanted the filth out of my body'.

67. I was told I needed to eat a high carbohydrate diet and my dental health and bloods monitored during the treatment.

68. The hospital was lovely. The consultant Dr Wong said it how it was and that worked for us. This is the difference between a carer and caring: these are similar words but they have a different meaning.

69. My platelet count by the time I was viewed as fit enough to start the 48 week treatment programme was around 53. It was agreed with my doctor that if my platelet levels dropped below 20 the treatment would be stopped.

70. I was told that I would have to self-inject the Interferon. My wife tried but I could see it distressed her and so I undertook to do it myself. The injections were once a week and I had around a two-hour window to do the injecting. I don't think it was critical that every injection was done exactly within the window, but it was my take on the self-discipline, that I felt I needed, in order to do the injections.

71. The advice of what would happen to me physically helped; however it didn't prepare me for the reality of treatment.

72. Treatment was like a bus that hit me. I was informed that I would have flu like symptoms and would experience pain. I was told everything and they tried to prepare us for it, but still we were panicking.

73. I took the first dose of Interferon by self-administration under supervision at St Thomas'. I injected myself around 3-4pm and was able to travel home but the effect started to hit around 8pm.

74. I experienced hot and cold sweats, terrible shakes, the pain was off the scale, I had headaches and nausea. To say it was like, classic flu symptoms is as close as I can get to describe the impact. I managed to get up my stairs when I returned home, but only because I went up the stairs as soon as I started to get bad.

75. The first three weeks were really rough. My wife had to change our bed three times following the first injection, because of my sweating and high fever. The tremors that wracked me were virtually off the scale and the body pain almost unbearable.

76. The effects would last for four-five days after the injection and would then ease off. By this point I could barely bring myself to inject myself again.

77. I was prescribed Coproxamol as pain relief, but the government withdrew this during my treatment, due to some patients with unrelated conditions taking overdoses. The substitutes for this drug had little to no effect for me and so I stopped taking them. I did however get the green light from the doctors for this decision. They were concerned that the medication may be causing further damage to the liver anyway.

78. A lot of my body fat disappeared after successive injections and it became progressively more difficult to find a site of fatty tissue to inject myself. There was a painful rash, in a band along my lower abdomen, which brought its own

pain when injecting. However I did what I needed to do. I can understand why lots of people did not finish the treatment.

79. I recall after approximately ten weeks of treatment developing almost unmanageable pain in my mid-section, around the hip area. This pain was exacerbated by, even very short walks. I recall experiencing this when walking from Waterloo Station to St Thomas' Hospital.

80. Due to the pain I was referred on to a Dr Mike Smith at the hospital. Dr Smith was a top paediatric orthopaedic consultant, who also specialised in people with bleeding disorders. Following an examination, Dr Smith referred me for an MRI scan of my lower lumbar spinal area to confirm his diagnosis.

81. On the day the results came back I tried to walk as usual from Waterloo to the hospital. I only got a few feet before nearly collapsing with the pain and my wife had to hail a taxi to take us the rest of the way to the hospital.

82. It was confirmed that I had developed a severe form of Neurological Claudication (Spinal Stenosis) "probably" as a result of the treatment, which from my understanding, attacked the virus in the bone marrow and promoted bone growth inside my spinal canals.

83. This was a side effect, which I was told, hadn't been apparent in other patients but could not be ruled out. I have noticed over recent years that clinicians are reluctant to give definitive causes, without completed, verified, research to back it up. As an engineer I can relate to that position.

84. As I did not want to stop treatment it was agreed that the doctor would operate on my spine as soon as possible after treatment had been completed.

85. Also, during treatment, I developed a regular and severe spate of nosebleeds. These were more of a worry to those around me than to me. I was however concerned on several occasions when they persisted, as I was losing a lot of blood.

86. These persistent nosebleeds have continued and are now what I consider to be a part of my life. In early 2018 they became so bad that after about ten days, I attended the A & E department at St Thomas' where I received a platelet transfusion.

87. I also developed severe leg and arm/hand cramps. I was eventually referred to a Neurological Consultant who, after extensive testing, diagnosed Cramp Vesiculation syndrome.

88. This is a condition that is fairly easy to treat, provided the patient has a healthy liver, by taking magnesium supplements. However this is not possible due to the condition of my liver. The magnesium would further damage my liver, to the point of causing liver failure.

89. I therefore have no choice but to live with the condition but usually manage to restrict the discomfort to behind closed doors. It does mean that on occasions I suffer excruciating pain in my feet, legs, arms, hands and back, as well as the abdominal area. My biggest fear is it will spread to my heart muscles, which I feel will be fatal. My condition does, during extreme episodes, cause muscular and joint bleeds.

90. After three weeks of treatment, my gastrology consultant met with me and my wife, along with my haemotology consultant and key nurse. I was informed that my platelet level had dropped to 23 and that my treatment was therefore going to be stopped. I had also in that short time lost around 42lb (19kg).

91. I argued in response that we had a verbal contract that I would stop if my platelet level dipped to 20 and I had 3 to go! If I stopped I told my doctor that I was virtually guaranteed to die. By contrast, if I was to go and due to the treatment, then at least it would be relatively quick.

92. I didn't convince my doctor though and he did stop the treatment. I knew I only had a two-week window during the treatment when I could stop before I reached a point of no return and to restart would be futile. This is because treatment is a, one chance thing, as the virus builds up its resistance.

93. As an aside, I have to say that the care shown at all times by the St Thomas' team went far beyond professionalism. They were not only caring but they cared as well. We would not have got through the very worst time without them.

94. The following week, I took a letter to my doctor at St Thomas Hospital. I had drafted the letter removing all responsibility from the clinicians, but requesting to restart the treatment.

95. Fortunately my haematology consultant said I had been clear enough the week before and subject to a further platelet count to show if there had been any worsening in the figures, she would restart the programme. My and my wife's relief was palpable.

96. I have severe fibromyalgia as another side effect of my treatment. This was diagnosed a few years after a continuing debilitation. I also have chronic fatigue and sleep issues. If I lay down for too long (4-6 hours) the nose bleeds start spontaneously.

97. I have poor blood circulation that leads to very cold hands and feet, even in warm weather.

98. I developed an umbilical hernia as a result of the Interferon injections and the severe body tremors I had experienced.

99. I discovered I was being given 50 percent more Interferon than was appropriate for my body weight. I had queried the figures and asked to see the calculations.

100. The medical rep for the drug company producing the injections was called in as the clinicians informed me that they were simply giving the dose they had been advised to give by the drug companies.

101. After some discussion and following the medical rep consulting with his Pharmaceutical company, it was agreed that I was on 50% higher than the maximal dose and that this was not appropriate. I had agreed that I was coping with the level of intravenous drugs and my levels were then kept constant and I believe that because of this high level the treatment was ultimately successful.

102. I was also switched to Interferon pens part of the way through my treatment. However the pens didn't work and I was unable to tell whether, and how much, medicine I had injected myself with.

103. I complained and refused to use them again and eventually was supplied with the interferon and syringes as before. The company that manufactured them then accepted that there was a fault with the pens. This might have been a one off, but there was no way after this episode that I was prepared to use the pens. I had a week of reduced treatment because of this.

104. We went every week for blood tests to check my viral load. We could see that the load was reducing. Two thirds of the way into treatment (around the middle of 2005) I was told that there was no sign of the virus, but that I needed to continue treatment as the virus might return. You knew that the treatment was working as everyone's faces were grinning.

105. I was told that it was a 48-week treatment. I was infected with Genome Type 1 and Type 4 Hepatitis C. I believe that these are the most virulent strains of the virus. Although I cleared the virus, the monitoring blood tests continue on a biannual basis.

106. I continue to have blood tests twice a year, being tested for HIV and Hepatitis C.

107. I have an intolerance of anaesthetics and analgesics, which is common in patients with cirrhosis. This leads to constant pain that cannot be relieved. Sometimes I am in so much pain that I disappear into the toilet so that my wife cannot hear me scream.

108. I experience general musculoskeletal pain and shooting muscular pain, alongside my fibromyalgia. These episodes can hit me anywhere at any time. It is like flesh being stripped from my bones. It happened on a plane once and they thought I was having a heart attack.

109. I am not allowed morphine as it could cause further damage to my liver. I was once prescribed pregabalin as an alternative. However this made me sleep for two to three days and so I haven't taken it since. I cannot take anti-

inflammatory drugs due to my liver damage, which is a problem as I am an arthritis sufferer.

110. If the pain is not due to my liver I just have to deal with it. An example is my gall stone pain flare up's, which are particularly painful. I have a relatively high pain threshold anyway though, or so I am told.

111. Because of my platelet levels, I have had to fight to get doctors to arrange for my hernia repair operation. This is because they are reluctant to do this.

112. In terms of the mental impact of my infection, this has been in many ways harder to cope with.

113. My initial reaction, after learning how the infection took place, was I wanted the "filth" out of me. A totally over the top feeling, which I still regret having. It came from my irrational reaction to learning that the blood, where the Hepatitis C came from, was from prisoners and drug addicts in the USA, who had been paid to donate it. This was and is not in my character under normal circumstances.

114. It distanced me, physically, from the loving relationship I had with my wife and isolated me from my children and grandchildren. I lived with the fear of passing the infection on to them; rational thought was not part of my thought process.

115. I felt I had failed my family in many ways. Had my business failed because I couldn't cope with being infected – yes. Had I infected my wife and previous wife? All worry's and stress at a time when I was ill.

116. **GRO-C**

117. Our relationship is very strong, and she wasn't giving up on me over it. She understands what has happened. She has supported me emotionally, financially and she has managed my physical health problems without thought or comment since the initial diagnosis. I don't know how I would have got through it without her.

118. The emotional and mental effects still persist and I regret that in some ways I can't get past them. Mentally I still suffer from low self-esteem, despite encouragement and support from my wife. I still feel I have let her down. She didn't sign up for any of this.

119. I have self-doubt when undertaking tasks. I often think in my mind that I will be unable to finish them and worry about having sufficient energy.

120. I was in my early 50s when I received the news about Hepatitis C. It answered a lot of questions but set new ones in train, I've never been able to get past. Would any of this have happened anyway? I don't know: more self-doubt.

121. I am regularly told I will have liver cancer in five years but then it doesn't materialise. The stress of this is unimaginable.

122. Due to my GP's failure to order the right blood tests, my diagnosis was made late. If I had been diagnosed earlier my liver probably would not have deteriorated so much.

123. The thing that most hacks me off about my late diagnosis is that the 'key man' insurance policy, which both my wife and I had, expired two weeks before the diagnosis. If the diagnosis had been made two weeks earlier I would have been entitled to a regular salary as part of the policy.

124. Following the diagnosis for the Hepatitis C, St Thomas' have given me and my wife, world class care and have provided a very rapid response to my condition.

125. I am now on a very low carbohydrate diet. This means I am not allowed to eat bread, rice, potatoes or pasta (or the products they use in their manufacture, such as wheat flour).

126. It is difficult to stick to this when eating out socially, so I tend to not go out a lot for social events or only attend ones I know I can miss eating without it being noticed.

127. I have now been diagnosed with fatty liver disease as a result of the cirrhosis, for which there is limited treatment.

128. I now want to talk about stigma. This has come from my political activity locally. I have been a councillor on and off since 1987, until I stood down in 2015. I was targeted in 2007 in a doorstep campaign to unseat me. We had friends phoning up asking what the matter was, as "someone on the doorstep" had said there was little point in voting for me, as I only had six months to live. This was very stressful for my wife.

129. I never tried to hide my infection or what was happening. I see it as helping others who were infected, to see that they have nothing to be afraid of.

130. My condition has had a drastic impact on my working life.

131. The problems started at least five years before my diagnosis. My wife and I had just completed buying our small high-end tooling firm from my former employers, a project I had worked on for around ten years.

132. Because of my tiredness, I felt I had no choice but to wind up my business. If I had not done this, then the bank would have wound up the business for me.

133. I was losing money because my brain was not functioning. I only realised this later on. To me this is where I feel like a failure. Things seemed too complicated for me at the time and I couldn't cope. I felt shit.

134. I also started taking salary breaks meaning I was taking no money home so that I could afford to pay my staff. Both my wife and I were on around £30,000 each before I got ill and this quickly dropped.

135. After the winding up of my business, I had a 6-8 week rest and then started looking for a job in late April 2002. I almost had to restart from scratch after my business had failed. We survived financially only because of a small allowance I drew as an elected District Councillor (£11,000) and because my wife was working as a CEO in a large charity.

136. I obtained an office manager job down in the industrial estate in GRO-C. I stayed in this role for ten days but left due to the way staff were treated and because I didn't trust the business.

137. I then found a job in GRO-C (which was £15,000 per annum) and was employed as a Business Development Manager. This was again low- end work and it was work I was not familiar with. However I am an electro-mechanical engineer and have always been able to talk to people, so I managed.

138. I spent the first few months closing contracts and making a lot of money for the business. However things didn't get better health wise and so I asked to be referred for the tests I have detailed.

139. Once I started treatment I was not able to work and have been unable to work since. I became industrially useless.

140. My wife was forced to give up work and take early retirement in order to act as my carer. This caused a significant financial impact.

141. Due to the risk of pain I have been unable to play with my grandchildren in the way that I used to. I am unable to have the same level of physical contact that most granddads have with their grandkids.

142. On one occasion my granddaughter was sitting on my leg and I screamed in pain as it hurt. I was nearly crying and my granddaughter didn't understand what had happened and was petrified.

Treatment/Care/Support

143. My Hepatitis C has on occasion, created barriers to treatment, when I have fallen outside the St Thomas' network. I had an eye operation at Brighton and Sussex Hospital in Autumn 2000 and was told that I didn't have VW which was frustrating as I have known that I have this condition for most of my life. A letter

dictated from Dr GRO-D on 9 October 2000, queries my VW diagnosis and suggests that I had normal results (**WITN0216007**)

144. The clinicians insisted that I was wrong and after a row they called St Thomas', who confirmed that I had VW and told the doctors at Brighton what to do in terms of treatment.

145. I was concerned that there was something wrong with their testing and I was later informed by Dr Savita Rangarajan, a Haemophilia Specialist, that one reason why the VW might not show up, is because Hepatitis C can mask the results, so the hospital should have carried out further tests.

146. The hospital should have queried why their test was not working. If they had done this, then it may have flagged up my Hepatitis C three years earlier.

147. Both my wife and I received psychological support from day one after my diagnosis by St Thomas'. We needed to have counselling and we were positively encouraged to get it. It was provided at St Thomas' by a specialist senior phycologist, Dr Heather Rawle. An aromatherapist even came especially from Brighton to help treat us. She was lovely.

148. This support has continued for my wife in the period leading up to and during my treatment. Mine has continued and carries on to this day. It will carry on until I feel I don't need it anymore. I'm not ready to give it up yet.

149. My psychologist is attached to the Haemophilia Department at St Thomas' and specialises in people with bleeding disorders. As soon as I have attended other centres and hospitals for treatment, where the clinicians do not specialise in work with haemophiliacs, I have found that care and a caring attitude seem to fall apart a little sometimes. This service should be available to all victims of the Contaminated Blood tragedy not just haemophiliacs.

Financial Assistance

150. I was informed that I could get financial assistance via the Skipton Trust, by St Thomas' and they filled out the forms for me and sent them off. I had no problems whatsoever and simply had to sign the forms.

151. I was not made aware of any preconditions for making an application.

152. I received an initial Stage 1 payment of £20,000. I then received a Stage 2 payment of £25,000 and then an additional £25,000 a few years later. The regular payments for stage 1 have only been paid over the last year or two.

153. Currently my payments are £18000 pa (£1500 pm). I also receive a top up payment of £134pm. I receive a winter fuel allowance of £519 paid around December. I also now have other occasional payments for specified reasons. I have attached a copy of the financial support from NHSBS for information. I

am however unclear if this is going to be ongoing support and if it is to be linked to CPI as in the past. The wording on the agreement, to me, seem ambiguous.

154. After I had stood down as a councillor I applied for Personal Independence Payment (PIP), as I was unable to work. I went for an interview to assess the level of my disability but was turned down. The letter explaining the decision was virtually calling me a liar. It was devastating. I did apply for a mandatory reconsideration but this came back with the same response.

155. I then contacted the Caxton Fund and they appointed an advocate to help me make an appeal to the tribunal. The tribunal overturned the decision to deny me PIP and I was put on the high level Living and Mobility Allowance.

156. I have claimed a one off payment to pay for roof repairs which we applied for. NHS Business Services paid for this. I have also claimed relief from VAT for disability alterations to my home.

157. I wish there was more equality in the payments made to infected and affected people in the UK. I also don't believe that the NHS should carry the full burden of the payments.

158. This was in a major way, I feel, a conspiracy by successive governments alongside poor to perhaps criminal practises, by some clinicians. The blood transfusion service was also complicit in this and should also answer some difficult questions on why they allowed the possibility of unsafe products to 'go out the door'!

Other Issues

159. I have contacted my local MP and my political community regarding my infection. I have written letters and sent emails to Sir Nicholas Soames, my MP and asked him to attend Parliament regarding the matter. He didn't however.

160. I have been asked by the Haemophilia Society to be a layperson on the Tri-Annual review of Haemophilia Centres across the UK. This is a United Kingdom Haemophilia Centre Doctors Organisation, (UKHCDO) project and I am only doing this work as a volunteer. I am receiving no payment and only expenses for costs incurred.

161. I have provided relevant extracts from my GP records and am able to supply copies of records obtained from St Thomas' and Sussex University Hospital Trust if needed.

162. As a former Councillor my life is an open chapter to the world and I do not therefore have a need for anonymity.

163. I have always been successful with my life but after my diagnosis with this disease I have felt like a failure.

164. Throughout my statement, I have referred to and described, certain documents. I have provided copies of these to the inquiry. I produce these copies, with the reference numbers listed below, as my exhibits: -

WITN0216002
WITN0216003
WITN0216004
WITN0216005
WITN0216006
WITN0216007

165. Finally, I have been asked if I would like to put any questions to the Inquiry, I would like to :-

a) When was recognition of there being a problem with the import of blood products? Dr David Owen, as Minister of State for Health in 1974, commissioned a UK facility to produce the different blood products. Would he have been so unmindful of the public purse to commit this expenditure if it wasn't necessary? What changed with successive governments to cause them to cancel and prevent this facility being completed?

b) Why wasn't the general population and specifically those with bleeding disorders, notified at the time and subsequently, by health professionals and government departments, including the Blood Transfusion Service?

c) *Some* Haemophilia centres/departments are actively seeking people who have had blood products from identified infected batches of products. Why has this not happened across the UK?

d) Those that have been infected and affected by this have had to prove they received the infection via the products. Why is the emphasis for this proof put onto very ill people, their carers and families and not those who supplied the products to disprove their liability?

e) Partners of those who have been infected have to prove their loved one died due to the infection, as I understand this, there is no gold standard of how to prove this. Does it mean dying due to liver disease/cancer. Conditions caused from the infection, or the conditions credited to the treatment?

This proof is dependent on them receiving a final £10,000 payment. I cannot see the logic in this, as they have cared for and in most cases, given so much and limited their lifestyles when sharing the load of the illness of those who have ultimately died. Why isn't continuing support given to the partners and those who have restricted their life opportunities as affected people?

Statement of Truth

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

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

Signed GRO-C

Dated 6th February 2019