



14 JAN 2019

Witness Name: Shaun AMES
Statement No.: WITN0361001
Exhibits: None
Dated: 5 December 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SHAUN AMES

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

I, Shaun AMES, will say as follows:

Introduction

1. My name is Shaun AMES. My date of birth and address are known to the Inquiry. I am a married man and have two children, one daughter and one son; their names are known to the Inquiry. Both of my parents have passed away.
2. I have two brothers and had a third; he has since passed away and was a sufferer of haemophilia as I am also. I live at home with my wife and our children. I was diagnosed with hepatitis C (HCV) in 1982.
3. I can confirm that I have chosen not to have a legal representative and that I was happy for the Inquiry team to take my statement.
4. In this statement, I intend to speak about my infection with HCV. In particular, I will go into detail about the nature of my illness, how the illness affected me, the treatment I received and the impact it has had on me, my family, and our lives together.

Infected Blood Inquiry
Fleetbank House, 1st Floor, 2-6 Salisbury Square, London EC4Y 8AE
contact@infectedbloodinquiry.org.uk
Freephone 08081691377

How Infected

5. I was infected with HCV in 1979 during an operation at Whitechapel Hospital in London to relieve complications of an earlier surgery performed at Southend Hospital.
6. In 1979 I was assaulted at The Elms Pub in Leigh-on-Sea where someone put a glass to my face. There are visible scars on the left hand side of my face as a result of this assault. I went to Southend Hospital to have it stitched up; a total of 57 stitches were applied.
7. The operation at Southend Hospital did not completely clear all of the glass from my face. There is residual glass. It eventually caused me to have a brain haemorrhage.
8. Consequently, I was sent to Whitechapel Hospital where they operated on me using infected blood clotting factor VIII.
9. In 1982 I received a letter from Dr. Colvin of Whitechapel Hospital's Haematology Department, informing me that my blood is infected with HCV. It was a typed A5 letter of only two to three lines. The letter has been lost over time and I no longer have access to it.
10. I was not provided with any further information, only that I was infected with HCV.
11. There was no support mechanism. Nothing was provided for me, just a diagnosis.

Background

12. I was born with haemophilia. GRO-C I am one of four boys; one of my brothers also had haemophilia. He has since passed.
13. From an early age I spent a few times in hospital, mostly due to joint and appendix related issues. A lot of it was tooth related in the early days.
14. When I was nine years old my teeth were overgrowing and they had to operate on them. I spent 26 weeks just having a few teeth out in hospital because of the bleeding.
15. There was no factor VIII then, just blood. Medically this is known as cryoprecipitate, a frozen blood product prepared from blood plasma-derived concentrates. It has since largely been replaced with the use of blood clotting factor VIII.
16. During the operation on my teeth I had four drips; one on each arm and foot. This is because my gums would not stop bleeding. I was

going through seven or eight pints of blood a day; it was going out of me, and they were putting it back in to me.

17. The schools I attended knew about my haemophilia. I do not think a lot of people understood what it was, or what impact it has on me, e.g. the fact that my blood does not clot. I do not think they understood it. There were no special arrangements at school.
18. Even the hospitals did not understand it. If I had a bleed, they just kept pumping me full of blood.
19. I came out of school when I was 16 and went straight to work.
20. Recalling the 1979 assault described in paragraph 6, and the subsequent hospitalisation that entailed, it was at Whitechapel Hospital in London where I first came into contact with Dr. Colvin. He later became a professor and is now retired.
21. After being told in 1982 that I have HCV as detailed in paragraph 9, I went to Whitechapel Hospital in London for treatment. Dr. Colvin subsequently became my primary doctor at Whitechapel. I would later also see Dr. Pasi.
22. I had many liver function tests. I had them all the time. The health care practitioners said they *"do not know if the liver is going to fail until it is within 10% of its life"*. I had several scans; I am surprised I do not glow to be honest.
23. I was subsequently tested for hepatitis A and B. The health care practitioners said of hepatitis A and B, *"There are traces in there but there is no proof of it"*.
24. There were many different hospitals I had to go to in London. Some of the hospitals have included Whitechapel Hospital, Whipps Cross Hospital in Leytonstone and St. Bartholomew's Hospital in the City.
25. There was a panel of people with ideas of what to do about my HCV. They would explain their ideas to me but their explanation lacked the confidence you would expect from health care professionals. The reality was they did not know what to tell me.
26. I was told, *"I will not make old bones"*. They said I had two years to live. They had essentially written me off, expecting me to die.
27. I was asked to reduce my drinking to help my liver. I asked, *"If I give up drinking will I live to 90?"* They said no.
28. I married my wife in 1991. In 1992 our daughter was born. In 1994 our son was born.

29. I remember a conversation with my wife in which she mentioned that she caught me crying in our bedroom when she was pregnant. I was crying because I thought I would not see our child walk down the aisle, if it were to be a girl. My wife mentioned that it shocked her because she had never seen me like that before.
30. In the mid-1990s we received the bombshell that my wife and our children could have been infected with HCV. This was communicated via another letter.
31. I recall my wife mentioning that she felt she had to go to the school and warn them that if the children cut themselves, if they fall over or hurt themselves and bleed, that the school staff are not to touch them without gloves on, until we know for sure. They said if my wife goes to get tested and is negative there is no way the kids have got it.
32.

GRO-C
33.

GRO-C
34. We really had to look up most of the information ourselves to be honest. There was no information given. I am not happy with how the information has been provided to me.
35. I have five years of documents showing that I have been pushed around from pillar to post, all because of a blood infection. I cannot emphasise enough that I have repeatedly been pushed around from one place to another.
36. It is frustrating. I cannot put into words how frustrating it is when you think there is hope at the end of the tunnel and then that hope is dashed when they shoot you down the other way, and then you go down another tunnel. There is no end to it.
37. To me that is the frustrating part: no one in the NHS can make a conclusive decision about what is wrong, about what to do.

Other Infections

38. I have been advised that I may have variant Creutzfeldt-Jakob disease (vCJD), a fatal degenerative brain disorder that in rare instances can be transmitted by blood transfusion.

39. I do not believe I have vCJD but I am in limbo. It is a possibility, it is like a lottery. I have the ticket for something but I do not know if I will get it.
40. The knowledge of potentially having vCJD affects me because I could have it, but I am not receiving any treatment for it.
41. I have been given no further information regarding the possibility of having vCJD. Nothing at all. I was only informed that I might be infected with vCJD.

Consent

42. I have had so many blood tests I do not know what they do with them. I do not know what tests they run or if they run any tests at all. It is possible that I have been tested without my consent but I have no evidence to suggest it. Anything is possible.
43. The operation they performed on me for the brain haemorrhage in 1979 went so wrong that they use it in a journal as a learning exercise for the NHS.
44. I am now being asked for consent. The first thing they ask from me before commencing a procedure is for my consent.
45. I was offered the opportunity to participate in a sleep study being conducted by a sleep clinic, in which they would test my lungs. In this case they asked for consent.

Impact

Mental and Physical Effects

46. The mental effect of being infected with HCV is that you do not know whom to turn to. Medical professionals have let me down.
47. I became depressed when my best mate committed suicide, and also when my brother died; that was even worse and I saw a psychiatrist for that. Then my aunt died as well. There were three deaths, one after another. Having to cope with this on top of HCV is a burden.
48. I have seen psychiatrists in Southend and Shoeburyness. Seeing one of these psychiatrists was a weekly occurrence. It was required due to the deaths, work related stress and the travel back and fourth to London; the sheer volume of pointless journeys was enormous. My travel back and fourth between Southend and London is detailed in paragraphs 71-77.
49. The physical effect of being infected with HCV is that I have lost a lot of weight, which is probably due to HCV.

50. I have had breathing problems and have seen my GP about this. Due to finding a shadow on my lungs, my GP referred me to Dr. Lingam at Southend Hospital's Heart & Chest Clinic for investigation.
51. I said to Dr. Lingam many times that I am not going to London just to be told the same result they have at Southend.
52. I have also been in a hypoglycaemic coma. Hypoglycaemia is a medical emergency in which the blood sugar drops so low that it can cause one to become unconscious, necessitating external support.

Further Medical Complications

53. My health has gone down hill over the past couple of years due to my lungs. My lungs are not as good as they used to be. I am often out of breath. This is because nobody can be honest to me about what is happening.
54. After the death of my wife's parents, I was at their interment at the cemetery with my wife and I said, *"It will be me next"*.
55. That is how you think; you give up in the end. It is a depressing situation in which you give up and you go into a shell. My head is in a bucket of sand.
56. In 2013 I was diagnosed with Chronic Obstructive Pulmonary Disease (COPD), an umbrella term used to describe progressive lung diseases.
57. In December 2015 it was suggested that I might have Wegener's granulomatosis with polyangiitis (GPA), also known as vasculitis, a rare condition in which the blood vessels become inflamed. It mainly affects the ears, nose, sinuses, kidneys and lungs.

HCV Treatment

58. In the early days I was treated as a leper. I do not think it is that bad nowadays; I think it was bad then due to the AIDS scenario. There was no privacy back then.
59. In 1995 I was told that there was a treatment, but not a cure, to try at Whitechapel Hospital, the hospital we always go to first. I asked what this treatment would entail; they said they did not know.
60. They gave me a list of potential side effects including liver failure and depression. The treatment would have involved having to take six months off work, regular travel to receive injections and to have blood tested. My wife mentioned to me that it is the same treatment Pamela

Anderson of *Baywatch* received; her indications disappeared after receiving treatment. However, I declined to receive the treatment.

- 61. My wife would describe my character as needing to be social and busy, and at that time I was showing no symptoms of the infection. My wife was concerned the treatment would cause me to fall into such a deep depression that I would commit suicide.
- 62. We looked at each other and said we cannot take that risk. The treatment was worse than the infection.
- 63. The health care practitioners came up with various ways of trying to cure HCV. For me, however, the process of curing it was worse than actually having it.

Other Treatments

- 64. I did not have enough information to consider whether or not there were other treatments, which I ought to have considered.
- 65. It is hard to say definitely because the information from the get go was not sufficient.
- 66. Consequently, I have received very poor medical treatment, especially in relation to cancellation of lung biopsy operations and other procedures, as outlined in paragraphs 127-141. This has had a negative effect on my health.

Impact on Dental Care

- 67. I have had difficulty accessing dental care.
- 68. Anytime I wanted anything done with my teeth it was a "no no". Nobody would treat me. You had to be fair and tell them the truth regarding my HCV, but as soon as I did, I was treated like a drug addict or like a leper. I do not do drugs and I am definitely not a leper.
- 69. The process of attempting to access sufficient dental care has been burdensome.
- 70. Pre-dental work I have to take factor VIII. Post-dental work I have to take tranexamic acid, a blood clotting tablet that prevents enzymes in the body from breaking down blood clots.
- 71. To access a normal dentist I must travel from Westcliffe to London Fenchurch Street Station and then to Whitechapel Hospital where I receive factor VIII treatment. I then travel back to Southend to see the dentist at Southend Hospital. All of this travel occurs within an hour and a half. It is required even for a filling.

72. The reason for this back and fourth travel is because the health care practitioners in Southend were too afraid to carry out factor VIII treatment.
73. On one occasion I completed the factor VIII process in London and then the dentist at Southend Hospital made me go back to London. This is intolerable. It is a joke. It is impossible.
74. During one dental appointment at the Whitechapel Hospital outpatient dental clinic, it was suggested that my teeth should be taken out. I reacted to what they told me and said "*I have had enough of this, up and down up and down for a filling*", indicating that it would be easier to just take them out. It would be less pain and less agony. My teeth were rotten anyway due to the inability to receive proper dental care over the years.
75. I had nine teeth taken out in one sitting. I had more teeth taken out in other sittings. A total of 22 teeth were removed. I have six teeth left.
76. During one sitting at Southend I had an argument with the dentist, as the dental practitioner did not want to do it. I had received factor VIII treatment at Southend Hospital and then went downstairs to the dental clinic, where the dentist refused to take the teeth out because there was no letter to confirm that the factor VIII treatment had been completed. I insisted that it had just been done, but the dental practitioner said they could not know, so I was sent home.
77. The removal of my teeth was at the behest of the dental practitioners; I wanted my teeth removed in one go to avoid the complications of having to travel back and fourth between Westcliff and London for so many teeth removals, although the period of removals still took years.
78. I was forced down this road because of the lack of care that has been provided for me. A lack of care and understanding.
79. The best dental care I received was at Southend College where the dental team was comprised of students. They were brilliant. They did not take any teeth out and did all of the proper checks.
80. The excellent dental care received at Southend College was after my teeth were taken out; they were going to build the dentures. However, I never got to the stage of having the dentures fitted. That is because nobody else would treat me and the college dental services were limited in regard to what they could provide.
81. Using the college's dental care was my only way forward at the time.

Impact on Eye Care

82. My eye was damaged from an early age when I had a pen thrown into the eye. It caused a cataract, which was taken out, but they could not save the lens. They tried another lens that sat on the outside but it has never worked. It is like having a bottle top in the eye and I never got on with it.
83. In the late 1980s, prior to the birth of my daughter, Specsavers referred me to the eye clinic at Southend Hospital for glaucoma, an eye condition where the optic nerve is damaged by pressure of the fluid inside the eye. Glaucoma can lead to loss of vision if it is not diagnosed and treated as early as possible.
84. I explained it all to them: haemophilia, hepatitis, this and that. They said there is nothing wrong with me and sent me home.
85. A year later I went back to Specsavers. The optician asked how I got on with the hospital. Not satisfied with the hospital's response, the optician referred me to the doctor, who referred me back to Southend Hospital for laser treatment. However, by then it was too late.
86. I did try to get the matter resolved at Southend Hospital. They provided a laser treatment option, which involved drilling nine holes into the eye to release the pressure on the optical nerve and save the eye. However, I was advised that it was two to three years too late. I am now blind in one eye.
87. The deterioration of my eye was because of the doctor at Southend Hospital who said there was nothing wrong with it. This is because the doctor did not want to treat me as I have HCV. They could not wait to get rid of me.
88. They took no tests; they just had a look, said, "*That's alright*", and sent me home. This is unacceptable.

Impact on Private, Family and Social Life

89. We do not discuss my condition as a family unit. We do not put a big sign on the door.
90. It has affected my family. Not my parents or brothers, but my immediate family.
91. We have never asked the children how the stigma affects them because it does not affect them in the way it affects my wife and I. We do not feel the need to discuss it with them.

92. We have always been open and honest with our children. They know what conditions I have and we have told them that if they have any questions they should ask. They have never asked.

93. If asked how I am doing, I usually say I am "*all right*". I am not all right.

Stigma

94. I feel that I have been tarred with the same brush, like I am a drug dealer or drug user or as if I have AIDS, or that I am "unclean". It is not my fault I am "unclean" to be honest.

95. Even if I went for a blood test, the nurses were so scared you could see them shaking just to take the blood; this was in London. On one occasion they had to get a sister/ward manager, because the nurse did not want to take the blood. They take blood all the time but did not want to in this case.

96. I have experienced the sort of stigma in which they clear an entire ward just for me to go in there, just to have a look at something, as if I will burst into flames if they do not take such radical precautions. The health care practitioners in these situations have no sympathy.

97. On one such occasion, I was at Whitechapel Hospital, at their outpatient ward where there is a dental clinic across the road. They cleared the whole floor of the dental department before they saw me in case I infected someone. There were 20 dental chairs and they had to clear it out. At the end they said "*We have to fumigate this now*" and I thought, "*What the hell have I got?*" I think that was over the top.

98. Whenever I have a health care appointment I produce two health care cards to the medical staff. The purpose is to inform staff about what I am dealing with.

99. The first is a Bleeding Disorder Information Card. It is a red and white plastic card.

100. The second is a Special Medical Card – Haemorrhagic States. It is a green, foldable paper card. It provides information about factor VIII.

101. When I present these two health care cards to medical staff, alarm bells go off, and then the health care received is a cursory look only. Every time I show these cards or tell medical staff of my conditions, I would say I receive no treatment. I get passed down the line.

102. They are more concerned with passing me on to another department rather than dealing with the issue at hand.

103. A lot of the time all you want is reassurance. You want to know what is the matter, but they do not even look at what is concerning me.

They just refer me to another hospital, as if I am a hot potato. I call this the hot potato syndrome.

104. As soon as you tell them hepatitis, they think, "*Oh hepatitis, oh AIDS*", they just do not want to talk to you and pass you off again. It is so annoying, so frustrating.
105. Socially I am fine as I do not need to mention it, but when I am in a situation in which I am going to see a dentist, or engage with healthcare associated workers such as the secretary or receptionist, the response is "*Oh you've got hepatitis*" and then it is like the whole room clears. That type of scenario. It goes back to the leper situation.
106. I do not think society has been as bad. I think the National Health Service has just swept it under the rug. They pass me from pillar to post. This is the hot potato syndrome.
107. There have been relationships in the family that have ended with the end result being accusations of HCV being passed on. That is why I do not put HCV out there socially, because it is a stigma.

Impact on Work

108. My employer at the time of my HCV diagnosis in 1982 was a builder's merchant. The director did not want me to go to work until Dr. Colvin of Whitechapel Hospital informed him I could not infect everybody.
109. Dr. Colvin wrote a letter to state that I could not infect anybody with HCV.
110. I could not become a policeman due to haemophilia, and there were certain others things I could not do such as join the Army.
111. There are certain other professions I am precluded from because I am a haemophiliac.
112. I have had to take a lot of time off work. My employer occasionally gives me time off, e.g. for an afternoon appointment, but if there is anything I have to go to London for, such as nuclear medicine where they inject you with radiation so you subsequently cannot be around people for at least two hours, they will not allow that; I have to use up my annual leave for those appointments. It mucks up my social life.

Financial Effects

113. The constant train fares has added up over the years. This has been a significant financial burden.

Treatment/Care/Support

- 114. I do not get any treatment, any care or any support.
- 115. No counselling has been provided to me in response to my condition. Recalling paragraphs 47-48, I have had to seek it myself.
- 116. Counselling was accessed through my GP.
- 117. The counselling occurred in Southend. They closed after I had finished my counselling. I think I probably finished them off to be honest. This was in the early to mid 2000s.
- 118. Since then I have not received any counselling. I am on antidepressants now all the time.
- 119. I was not aware of the Red Cross scheme. The investigator has informed me of the scheme, discussed it with me and provided me with a Red Cross contact card. I will consider taking it up.

Inadequate Treatment

- 120. The treatment provided by health care practitioners in regard to my haemophilia and COPD has been inadequate.
- 121. When I had cryoprecipitate provided, it was provided in a large yellow capsule. It was freezing cold. Administering it was a slow process that took several minutes. The health care practitioners at Southend Hospital would rush this, unaware that the process should be slow.
- 122. They changed the cold cryoprecipitate to a factor VIII concentrate. There were two versions: a man made one and one made from pig's blood (porcine recombinant factor VIII). I have an allergic reaction to the pig's blood. Nine times out of ten they gave me the wrong one, the pig's blood. I am supposed to have concentrate, which I am ok with.
- 123. As an example, in the 1980s I had been in intensive care for a rash. During this hospitalisation, the health care practitioners gave me the wrong factor VIII. Furthermore, the treatment for the rash was antihistamine and the factor VIII had to be provided in tandem but it was not.
- 124. I did not receive an apology. They just sent me home, they did not even tell my wife.
- 125. When I was diagnosed with COPD, recalling paragraph 56, they took various MRI scans at different hospitals, the first being Southend Hospital, followed by Whitechapel Hospital, then St. Bartholomew's Hospital and Basildon Hospital. I have numerous appointment letters showing where I was passed around. Basildon Hospital was willing to

- perform the lung biopsy but when they contacted Whitechapel Hospital they were told not to touch me.
126. I believe this process of being passed around is down to haemophilia and HCV, because they do not know how to deal with it.
127. I waited nearly five years to have a biopsy on my lung. They decided to do a biopsy at Southend Hospital. They would not take the chance to do it under general anaesthetic, so they offered it under local anaesthetic. They did this because they thought that due to the state of my lungs I would never come out of it.
128. In-between this time I was pushed around between many different departments. They put me in the ear, nose and throat department; I have no idea what that has to do with lungs.
129. Then they put me in the rheumatology department, who sent me to London, where I was subsequently sent back to Southend.
130. Upon being sent back to Southend, I was once again referred to the ear, nose and throat department, and yet again referred to rheumatology.
131. I was subsequently sent to another department where they finally said they would do the operation. They booked me in for day clinic surgery and had the factor VIII ready to go. Then they pulled the operation.
132. The doctor who was going to perform the operation said they could not do it. I cannot remember her name.
133. The doctor said, *"We cannot do it because it has been brought to our attention that you may have contracted vCJD due to blood transfusions and it would cost the NHS too much money to do it because it would mean throwing all the equipment away after we have done it, so we will rearrange it with disposable medical material"*. They wanted to reschedule using disposable equipment.
134. I have been summoned to the hospital three times to have this lung biopsy operation. I have been turned away each time.
135. The first time Southend turned me away as they could not afford it.
136. The second time Southend rescheduled, as they did not have disposable equipment.
137. The third time Southend rescheduled again just to tell me they do not feel confident enough to do it. They referred me to Basildon Hospital.

138. I do not know how many times I swore. I was scared. I can never trust Southend Hospital after all these decades of not being treated correctly.
139. It made me pissed off. It made me feel frustrated. It was a lack of care once again. I perceive their mentality as being, *"Oh well, he is just another patient, he will come back"*, because I have nowhere else to go. I cannot go to the local supermarket to get the equipment. I have to go back to them; the reality is I have no alternative.
140. Following that all they did was refer me back to Dr. Lingam at Southend Hospital's Heart & Chest Clinic. Recalling paragraph 50, I was originally referred to Dr. Lingam by my GP after a shadow on my lungs was detected.
141. In regard to the cancelled lung biopsy operations, I feel I have no choices. I had to accept what they said. However, this is not acceptable to me. I am a human being and deserve treatment.
142. I have become used to the frustration, used to going to the hospital in London and seeing that they are not ready. However, getting used to this does not make it acceptable. Their behaviour does not instil confidence.
143. Because the health care practitioners could not conduct the lung biopsy, in December 2015 they advised me that they thought there could be four things wrong:
- (1) Rheumatoid arthritis. This is a long-term condition that causes pain, swelling and stiffness in the joints. It was suggested I had this in combination with rheumatoid nodules, which is local swelling or tissue lump. This was discounted.
 - (2) Aspergillosis. This is a condition affecting the lungs that is common in people with COPD. This was discounted.
 - (3) Nasal polyps. These are soft growths inside the nose. This was discounted.
 - (4) Wegener's granulomatosis with polyangiitis (GPA), also known as vasculitis. Recalling paragraph 57, this was the condition they settled on. Vasculitis is a rare condition in which the blood vessels become inflamed, affecting the ears, nose, sinuses, kidneys and lungs.
144. The suggestion that I may have vasculitis is all guess work because they cannot do the lung biopsy. They accept the biopsy needs to be done but nobody wants to do it, so their best guess is I have one of these four diseases. They went through them and discounted three.

145. In October 2017 I went to the Royal Brompton Hospital for a fluid biopsy at a unit associated with St. Bartholomew's Hospital.
146. On another instance, because they could not do a lung biopsy, the health care practitioners flushed my lungs out instead. The purpose of the operation was to flush the lungs in case there were signs of problems. However, they ended up flooding my lungs instead.
147. I spent the next four days in intensive care with pneumonia because they flooded my lungs instead of flushing them. I have never recovered properly since.
148. This has had a severe impact on me to the degree that I have no alternative but to give up work earlier than when I wanted to. It has had a negative financial impact.
149. I feel that I do not get any results. On the last occasion when I went for my liver function test in 2017, I had my paperwork, passed it over to the man and he said, "*We don't have anybody here to do it.*" They ended up getting someone to do the test, but I have not heard anything from it even to today's date. I do not know what is happening with my liver.
150. The NHS as an organisation is not very good. They are not very good because the customer care is bad. In regard to patient care, they do not seem to care. It is bad.
151. To provide an example, on one occasion they rang my mobile. When I answered, they said, "*You're still here then.*" I have no idea who that was on the phone.
152. In terms of how the medical staff should communicate with me, this is not a good way to communicate. It is as if they did not expect me to be here, or hoping not to be here from a cost perspective. It is an appalling way to treat somebody over the phone.
153. Health care practitioners often claim I have disappeared from their radar, but we have lived in this house for 30 years. They know where I am and I know where they are.
154. They should have the confidence to say, "*This is how we are going to do it*", not "*This is how we think we are going to do it*", only to pass me on again and again.
155. I was offered the opportunity to participate in a sleep study being conducted by a sleep clinic, as mentioned in paragraph 45. I have spasms at night, and the study would have investigated this. However, recalling paragraphs 146-148, after the incident in which my lungs were incorrectly flooded instead of being flushed, I did not want to proceed.

156. The reason I did not want to proceed is due to the poor treatment I have received. I decided that I would not put myself at risk of experiencing that again. I did not want to go to the sleep clinic because I was not getting any answers in general from the system.
157. My confidence in the system is shot.

Financial Assistance

158. I have received financial assistance from The Skipton Fund.
159. I found out about The Skipton Fund when I received a letter from the government. They told me that I would be contacted by The Skipton Fund. My wife filled out the forms and sent them off.
160. I was given a one off payment of £15,000 in 2003. The Skipton Fund advised that if I die there would be additional funds made available as a consequence of dying due to HCV.
161. I was not given monthly payments with The Skipton Fund. I started receiving quarterly payments after 2003.
162. In 2015 I was granted £500-£600 per quarter and a £300 winter fuel allowance was introduced; the winter fuel allowance continues to the present. It has now increased to a £500 winter fuel allowance.
163. In 2017 I was transferred to the England Infected Blood Support Scheme (EIBSS) and now receive financial assistance from them. The amount is £1000 every quarter and £500 winter fuel allowance.
164. My wife completed the process of applying to the funds. She filled out the forms. The forms ask what phases of HCV I am in; we do not know as nobody has told us. It is not a case of us not wanting to ask what phase, but rather that we do not know who to ask.
165. Consequently, when filling out the forms to apply for financial assistance, my wife asked for a basic package because we did not know if we could go for anymore.
166. There were no difficulties transitioning to EIBSS. They knew I was infected as the government had contacted me, presumably due to my haemophiliac status.
167. Regarding preconditions, I do not get the impression that there were any preconditions imposed on the making of an application for, or the grant of, financial assistance.

168. I have worked hard all my life and I have no benefits. I do not classify the fund payments as a benefit; I view it as a payoff from the government or the NHS because of their negligence.
169. I have discussed with my wife the fact that I have always worked and if I had not had the operation in 1979 I would be dead, so I have never asked for money, I have always worked. That is my way of dealing with things, but there are others my wife knows of who did not work and had all the benefits under the sun.

Other Issues

170. I have not been involved in any litigation or any other inquiries.
171. The only thing that really gets to me is when the funds say, "*If you die from this infection we will give you X amount*". I think why not give me that X amount now and be able to enjoy my life?
172. I choose to work and I do not want to be a burden on the NHS. They have a lot to worry about other than me.
173. Regarding how the government has managed the process, I feel that we are stuck on the outside, and that our concerns go into the big government machine. They cannot even get us out of Europe let alone fix this. How they organised this inquiry I do not know.
174. I have discussed with my wife the fact that we do not know what is going on with the inquiry.
175. As a point of information, there is a 'Haemophiliac Tree' at Whitechapel Hospital in London that displays everyone who is a haemophiliac, including myself.

Statement of Truth

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

Signed

GRO-C

Dated

12/01/19

