



Witness Name: Martin BEARD
Statement No.: WITN0012001
Exhibits: **WITN0012002**
Dated: 14 November 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MARTIN BEARD

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 14 November 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Martin BEARD, will say as follows: -

Introduction

1. My name is Martin BEARD. My date of birth and address are known to the Inquiry. I am a single man and have never been married. I have two brothers and I am the youngest. I was diagnosed with haemophilia when I was six months old. I live at home with my mother
GRO-C
2. 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.
3. In this statement, I intend to speak about my infection with HIV. 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.
4. I will also speak about my CD4 count, which provides a snapshot of how well my immune system is functioning. CD4 cells are white blood cells that fight infection. A normal CD4 range is between 500-1500. HIV impairs CD4 cells.

Infected Blood Inquiry

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How Infected

5. It is my belief that I was infected with HIV through contaminated clotting agent factor VIII blood products. Factor VIII is an essential blood-clotting protein used for the treatment of haemophilia.
6. I started factor VIII in 1974 when I was five years old.
7. The earliest record of me being HIV positive dates to 1983 when I was 14 years old.
8. I was not informed of my HIV status until 1 September 1986 when I was 17 years old.

Background

9. When I was a baby I started to develop a lot of bruising, leading authorities to believe that I was being abused. They started asking questions and my mother informed them that there was a bleeding disorder in the family. GRO-C
GRO-C
10. Upon hearing of the history of haemophilia GRO-C I was then sent for various tests. It was during this time that I was first diagnosed with haemophilia. The results of the test revealed that I was a severe haemophilia A sufferer. I was six months old.
11. As a child growing up my mother always wanted me to lead as much of a normal life as possible; the normal rough and tumble play that kids have. However, I spent a lot of time as a youngster in the hospital with bleeds because back then I was not on home treatment.
12. Home treatment involved the use of concentrated factor VIII stored in a domestic refrigerator and injected when and where required. I would not start home treatment until 1976.
13. The nearest hospital for me was Birmingham Children's Hospital. This involved a lot of travel from Burton-on-Trent to Birmingham whenever I had a bleed or injury.
14. The only treatment that was available at that time was cryoprecipitate, a very crude clotting agent discovered just after World War II. The problem with cryoprecipitate was that I had an allergic reaction to it, causing me to vomit. The doctors tried to alleviate this with Piriton (chlorphenamine) but it never worked for me.
15. In 1974 I was at Birmingham Children's Hospital with my mum. After I had been given my treatment, the consultant explained that they had been given permission to administer factor VIII to me in response to my allergic reaction to Piriton. I subsequently started factor VIII

treatment; however, it still involved travelling to Birmingham every time I had a bleed or injury.

16. In 1975 I lost six pints of blood from a head wound and I was close to death. I was in a bad way. That was something that still sticks with me to this day. My brother had found me that morning and thought I was gone. That is how things were for me back then.
17. In 1976 things changed when the doctors and nurses at Birmingham Children's Hospital started training my mum how to treat me with factor VIII. This was a prelude to the commencement of home treatment.
18. However, my GP at the time refused to allow me to begin home treatment. Consequently, we ended up changing GPs in order to facilitate home treatment.
19. Upon changing GPs in 1976, I subsequently began factor VIII home treatment that same year. This enabled us to bring factor VIII home and keep it in the fridge. My mum would treat me at home as required.
20. In 1986 I had to leave Birmingham Children's Hospital because I was now an adult. Normally, patients who leave Birmingham Children's Hospital would be sent to Queen Elizabeth Hospital in Birmingham. However, the doctor I was under at Birmingham was a good friend with a doctor at Staffordshire North Infirmary and thought it would be more convenient for me to travel there. I do not know why because it was a longer journey. However, I agreed anyways.
21. My first appointment at Staffordshire North Infirmary was on Monday 1 September 1986. I went to the appointment with my mother. We sat in the waiting room and were called into Dr. GRO-D office. The door remained open allowing people behind me to hear the conversation. The doctor said, "*Good morning, I see you are HIV positive.*" Just like that. I looked at him, looked back at my mum and said "*well that's life*".
22. Dr. GRO-D said, "*that is your life for the next two years*". He said I have two years left to live. That is when it hit me and I went into a state of disbelief after which I cannot remember a single word he said to me.
23. Upon reflection I struggle to understand why a health care professional would announce my condition in the hearing of other patients. This was confidential information and I find it quite hurtful that other people were made aware of my condition. I also believe his bedside manner to be lacking in empathy and sympathy.

24. We came home from the hospital and the first thing I did was tell my brothers. However, I cannot remember what their reaction was. I was still in a state of shock and disbelief. I thought it was bizarre that someone as healthy as myself at that stage in my life would be told that I only have two years left to live.
25. I subsequently contacted a solicitor to make my will out at only 17 years of age. I thought the only people who do that are soldiers.
26. I was not sexually active so I did not have to worry about whether or not I had infected anyone. I carried on with life pretty much as normal.

Other Infections

27. In 1994 Dr. Chris Conlon of the John Warin Ward at Oxford's John Radcliffe Hospital informed me that I was infected with Hepatitis C. However, he advised that I had spontaneously cleared it.
28. Dr. Conlon asked if I had been vaccinated against Hepatitis A and B. I said no and he advised that the John Warin Ward would be in touch with the Derby Royal Infirmary to provide Hepatitis A and B vaccinations.
29. Derby said they would not provide the vaccinations because they were too expensive.

Consent

30. I was tested for HIV without my knowledge or consent. This is indicated in a letter, referred to as **(WITN0012002)**, signed by Dr. V.E. Mitchell, Consultant Haematologist at the Leicester Royal Infirmary, dated 11 October 1985 and addressed to Dr. D. Perry, Senior Registrar in Haematology at Birmingham Children's Hospital.
31. Dr. V.E. Mitchell wrote in the fourth paragraph, "*We note that he (Martin) is HTLV 3 antibody positive, but is not aware of this and that you do not wish this to be divulged to him. We shall make every effort to comply with your wishes.*"
32. I did not see this letter until I had access to my medical records.
33. I have experienced a two-tiered system in regard to receiving information. I would rate Oxford as excellent; I have been under them for 27 years and the care I have received has always been superb. I trust the information received from Oxford. On the other hand, my experience at Birmingham has been inadequate. At Birmingham, information was withheld. However, the care was good.
34. I believe I have been tested for the purposes of research without my consent or knowledge. When I look through my medical records and

see how often they took blood tests for hepatitis and varicella (chicken pox) it looks unusual.

35. Having looked through my notes, there were so many blood samples taken as an outpatient and I think the sheer volume is unusual. However, I cannot be certain that these were used for research.
36. Nowadays at Oxford if they are ever doing anything like that they ask me to sign something.

Impact

37. The mental effects of being diagnosed with HIV have primarily been a lack of confidence, specifically in regard to meeting a life partner and having a fulfilled family life. There have been numerous physical effects as a result of associated infections and side effects of HIV treatment, which are detailed below.

HIV Treatment

38. My initial exposure to treatment for HIV was in 1994. I went to the Derby Royal Infirmary for a routine HIV blood test, during which the two doctors gave me a bottle of pills. They told me the pills were AZT (azidothymidine), also known as ZDV (zidovudine). I was reluctant to take the pills as it did not feel right to me, but the doctors insisted that they thought I would benefit from them. I took the pills home.
39. Before starting AZT, I decided to seek a second opinion from a haemophiliac doctor at the Oxford Haemophilia and Thrombosis Centre (OHTC). I had first come into contact with the haemophiliac team in Oxford in 1992 after my mum referred me to them in 1991.
40. In 1991 I was at the Derby Royal Infirmary with a knee bleed. They wanted to give me a knee replacement but at only 22 years old I was hesitant; I was a healthy, slim athletic person. We decided to get a second opinion from OHTC as one [GRO-C] had once been transferred to Oxford where he sadly passed away.
41. The doctors in Oxford told my mum that if any member of her family ever has a problem in the future, they should come to Oxford for advice. In 1991 when the team at Derby Royal Infirmary suggested that I have a knee replacement, my mum wrote to Oxford seeking their assistance, noting that they had treated [GRO-C] [GRO-C] in 1976.
42. I was subsequently invited to go down to Oxford in January 1992 to see the haemophilic team at OHTC. I met with Dr. Charles R. Rizza, who treated [GRO-C] in 1976, and Dr. Paul Giagrande. They informed me that I was too young for a knee replacement and suggested knee surgery instead. They requested that Derby Royal

Infirmary pay for it as I was under their care; this was approved, and I went to Oxford in June 1992 to have an arthroscopic knee washout.

43. Consequently, I effectively became a haemophiliac patient under the care of Oxford. However, I was still under the care of Derby for my HIV appointments. It remained this way for the next three years.
44. I did not have any major issues with my HIV care at Derby until 1994 when, as mentioned above in paragraph 38, it was suggested that I begin taking AZT. I was reluctant to take Derby's advice to take AZT alone, hence my decision to reach out to Oxford for a second opinion, as I trusted their judgement.
45. I phoned the haemophiliac team in Oxford asking for advice. They passed me onto Dr. Chris Conlon of the John Warin Ward for HIV treatment at Oxford's John Radcliffe Hospital.
46. Dr. Conlon advised me that they do not provide medication to patients unless they really need it. Dr. Chris Conlon invited me to Oxford for an HIV review, noting I already came to Oxford for my haemophiliac treatment.
47. During my 1994 consultation with Dr. Conlon, he said, *"I see you are HIV positive and I see you have been infected as early as 1983"*. I asked if he had any idea as to when I had been infected, to which he responded *"We don't know when exactly, that's the earliest we have on record"*.
48. Later in 1994 my cousin who was also a haemophilic and also HIV positive went to the Derby Royal Infirmery where he was offered AZT. He struggled to deal with the side effects but took AZT anyways. Within six months he was dead.
49. On 2 August 1995 I went to Oxford with a very painful left knee. They did another washout, recalling the first arthroscopic knee washout at Oxford described in paragraph 42. However, this time they performed a synovectomy, an advanced knee washout.
50. In 1997 I admitted myself into the John Warin Ward in Oxford because my HIV was starting to get a grip on me; I had lost a lot of weight. My CD4 count, which is how they measure your immune system (a normal level being between 500-1500) was down to 70. I had a few infections as a result of my HIV condition. The first thing they did was deal with the infections and sort them out.
51. After dealing with the infections caused by HIV, Dr. Conlon said, *"I think you are going to have to get around the thought of having to start some sort of medicine regime."* I have never been a pill taker, avoiding them whenever possible, so this was a big change for me. However, I knew it was a case of get on board or die.

52. The John Warin Ward at Oxford put me on a double range of pills: the first called Videx (didanosine) and the second AZT (azidothymidine). Recalling my reluctance described in paragraph 38 to take AZT alone from the clinic in Derby, this time I was willing to take AZT in combination with Videx as I trusted the judgement of Dr. Conlon.
53. The regime involved taking Videx and AZT three times per day, an hour before food or 2 hours after food, which can play havoc with your day-to-day life at times.
54. I was on Videx and AZT for two years from January 1997 to the beginning of 1999. My CD count went up from 70 to 450. I put on about three and a half to four stone in weight.
55. In 1998 Oxford decided to change my medication from Videx and AZT to Crixivan (indinavir). This was one of the major breakthroughs in HIV treatment but it had a lot of side effects that were unknown at the time.
56. One of the main side effects of Crixivan is lipodystrophy, which will affect me for the rest of my life. Lipodystrophy causes abnormal fat distribution in the body. It takes the fat off your arms, legs and backside and puts it on the back of your neck, around the stomach and also internally around the organs. It is irreversible.
57. Upon returning from a trip to the United States, I had developed back pains and was admitted into Oxford in late 1999 with kidney crystals as a side-effect of Crixivan, which requires drinking between 3-5 litres of water a day otherwise kidney stones can develop.
58. The three options open to me were 1) flush me out with a drip, 2) have a laser projected up the penis to burn the crystals out, or 3) surgery. Thankfully they managed to flush them out over a few days, which was painful but the lesser of the three evils.
59. Whilst on Crixivan I developed a painful large ingrown toenail on my left foot. I went to see Dr. Chris Conlon in Oxford about this. I had known Dr. Conlon for about five years and it was the first time I had seen him look puzzled. He informed me that I was the third patient of his on Crixivan to have developed a large ingrown toenail. It was officially recognized as a side effect of Crixivan.
60. When I recovered from the flushing out of the kidney crystals, the team at Oxford decided to change my medication. They put me onto Viracept (nelfinavir). The side effects of Viracept were nowhere near as dramatic as Crixivan, but it did cause a lot of diarrheal problems.
61. Whilst in Oxford for the treatment of an ingrown toe nail as a side-effect of Crixivan as described in paragraph 59, Dr. Tim Peto of the

John Radcliffe Hospital asked if I had heard of the ESPRIT (interleukin-2) trial. I said no, and he indicated that it is a series of injections over a week to stimulate the immune system and boost CD4 count. He said it could only be given to HIV patients with a CD4 count of 400 or more. As I had a CD4 count of more than 400 I fit into this category. I said if it will help I will try it. Dr. Peto advised that it involved two subcutaneous injections per day and that after a week they would take blood to see if the CD4 count had gone up.

62. Dr. Peto warned that there would be side effects. He gave me a list of 16 possible side-effects including diarrhea, fluid retention, vomiting, painful rashes around injection sites, loss of appetite, fevers and aching joints. I experienced all known side effects of ESPRIT.
63. When I went back to Oxford after completing the ESPRIT trial, my CD count went up from 450 to 1300. I felt like superman. However, over the next 6 months my CD4 count dropped down to 600.
64. One of the reasons for the ESPRIT trial was to find out what my base level CD4 count was. They estimated mine to be around 700, but nobody knows for sure as they did not know my CD4 count until I was infected with HIV.
65. Over the next few years, I had more ESPRIT injections but in a lesser dose to minimise side effects. My CD4 count levelled out to around 700.
66. After the conclusion of the ESPRIT trial, I then went onto Viracept. The only major side effect was diarrheah. I continued on Viracept until 2014 when I went onto Truvada (emtricitabine / tenofovir).
67. In 2017 I switched from Truvada to Triumeq (abacavir / dolutegravir / lamivudine). It is three pills all in one. That is what I am on at the moment and I seem to be coping very well. My CD4 count is in the mid-800s.
68. I cannot say I have had any difficulties or obstacles in accessing treatments. I have been fortunate. The Oxford experience has been great. To provide an example, I had an operation on my left arm at Oxford where the experience was brilliant. When I phoned the professor at Oxford to ask if he could do surgery on my right arm, he was initially not available to take my call. However, he phoned me back and apologised, and said the surgery would be available within 6 months. He booked me in right away.
69. Recalling my initial exposure to HIV treatment at the Derby Royal Infirmary as described in paragraph 38, I do not believe they should have prescribed me AZT alone. I did not trust their judgement hence my decision not to proceed with their advice, and to instead proceed

under the care of the HIV team at the John Warin Ward at Oxford's John Radcliffe Hospital.

Impact on Dental Care

70. My HIV status has impacted my dental care. I cannot remember the year, but I went to a local dentist in Burton-on-Trent who I had been under for a while, complaining about a toothache. He x-rayed me and said there was no problem.
71. The next time I was in Oxford, I told them about my toothache and they had me see their dentist there. They said I had two wisdom teeth pushing through at strange angles. They did not understand how my local dentist in Burton did not know this. I was subsequently admitted to a dentist in Oxford where I had my wisdom teeth removed.
72. My local dentist in Burton knew about my HIV status. I believe my dentist in Burton did not want to treat me because of my HIV status. It is unacceptable that my own dentist would hide impacted wisdom teeth from me, a major dental problem that requires corrective surgery.

Impact on Private, Family and Social Life

73. My brothers do not talk about my condition. They will not discuss it with me; they never use the HIV word. My eldest brother just calls it "the lurgy". NOT RELEVANT
NOT RELEVANT
74. I try to talk to my brothers but I just think they have known me for their whole life and it feels like a wall.
75. My dad was mentally weak with his own psychological problems. I read one of his medical letters and it said my dad could not cope with the fact that I was not "normal".
76. The letter from Dr. John Stewart of the Birmingham Children's Hospital Haematology Department to Dr. G. Mills states "*I understand that there are some family difficulties, in particular that Mr. Beard finds it difficult to accept that Martin is not normal*".
77. In 1994 my cousin who was also a haemophilic and HIV positive died within six months of commencing AZT, as detailed in paragraph 48. I remember going to his funeral and all the family members staring at me; I could feel them thinking "*how long's he got?*"
78. In 1995 while I was in Oxford for the synovectomy described above in paragraph 49, I started a relationship with the nurse who was looking after me. When I was discharged after a couple of weeks we got

together and she moved up to Burton-on-Trent, where we lived together for almost a year.

79. However, I always knew there was going to be problems because in the future she would want children. It was not the fact that I was against the idea of children; it is just that I knew it was going to be problematic.
80. In September 1996 I made the decision for us to separate so that hopefully she could go off and have children, which thankfully she did and she seems happy. After this I went into a downward spiral.
81. In January 1997 I started taking Videx (didanosine) and AZT (azidothymidine) on the advice of Dr. Conlon of Oxford, as detailed in paragraph 52. Taking these pills in public had an adverse impact on my social life.
82. One such incident involving Videx and AZT was when I was out with friends for a few drinks at a pub. The only way I felt I could take these large pills was to crush them up. I did this at the pub utilising some foil and white paper; I had some funny looks, so I never did that again.
83. I have always tried to be open with people. The way I look at it is I am 50 years of age in January 2019 and what has happened to me is crap but if I meet people for the first time, I can gage what they are like, and sometimes I will tell somebody about my status.
84. Some years ago I was in a local chip shop in Burton waiting for an order. Within 10 minutes I had told a man about my HIV status. I said, *"look, if you want to ask me a question mate, ask, you won't have many opportunities"*. I think it is not everyday you bump into someone who will be as open and honest as I have been about my condition.

Stigma

85. In early December 1987 I was admitted to the North Staffordshire Royal Infirmary with a bad knee bleed. I was immediately put into a side ward and when the staff brought my meals they were in full NBC (nuclear, biological, chemical) style suits with masks and everything. When they brought my factor VIII in they would bring it in unmade and I would have to treat myself.
86. Everything they were doing at North Staffordshire just felt wrong. Whenever I had been in Birmingham Children's Hospital with a knee bleed, they would treat me without any masks or any of that rubbish, they would put ice on my knee and give me physio. In contrast, at North Staffordshire the first thing they did was put my leg in plaster. This goes against everything Birmingham Children's Hospital had ever done in regard to getting a haemophiliac's joint mobile again.

87. I was in there for two weeks just lying there getting weaker. Eventually I thought I cannot be dealing with any of this. I discharged myself on 17 December 1987. I had never done it before and I have never done it since. I discharged myself because I was not happy with the care that I was receiving, and I use the word "care" very loosely.
88. The December 1987 experience at North Staffordshire was my first real sign of any real stigma and isolation from the medical practitioners in regard to my HIV status.
89. I did not want to go back to North Staffordshire. From then onward, from December 1987 to April 1988 I was without a hospital to go to. My GP eventually got me under the care of the Derby Royal Infirmary in April 1988. This lapse in hospital coverage was a direct result of the stigma I experienced at North Staffordshire Royal Infirmary.
90. In 1987 I was an up and coming pool and snooker player in the local Burton area. I was good and won awards at the county and national level. I put an enormous amount of effort into playing pool and snooker.
91. I had been playing pool at the Crown in South Derbyshire for about 6 months. One night, I went in there to play my match and GRO-D said, "You, out, you're banned."
92. I went home after being banned and I felt empty, sick, dead inside basically. However, one of the most remarkable things about human beings is you can be kicked down but there is somebody there to pick you up. Within half an hour to an hour of me being at home after being banned from the Crown, another public house, which is just a 10-minute walk down the road from the Crown, asked me to play pool for them. However, this event still left me with a big emotional scar.
93. The incident at the Crown made the local newspapers. I display here a copy of the newspaper *The Advertiser*, dated Wednesday 30 September 1987, no. 362. The headline states, "AIDS Scare Youth Ban". Below the headline is a picture of myself on the front page.
94. The article states, "A Burton teenager with a rare blood disease has been banned from playing pool at the South Derbyshire pub. Martin Beard (18) who suffers from haemophilia was told he could not play for the team at the Crown Inn in Princess Street because of a fear he carries the AIDS virus." I now use this newspaper article as an educational tool when I perform public speaking.
95. In 1998 I wanted to travel to the United States for a holiday to the Grand Canyon. I asked the team in Oxford about it and they advised that I would need a visa and to be open and honest about my HIV status with the US embassy. I was refused a US visa.

96. Despite this, I kept applying for a US visa and was eventually granted a two-month visitors visa. In August 1998 I was able to successfully visit the US with my cousin, spending time in San Diego, the Grand Canyon and Florida. In my kitchen I display a picture of myself taken at the Grand Canyon.
97. When I came back from my trip to the US, a friend of mine told me he was getting married the following year and wanted me to be his best man. The problem was he was getting married in Florida. I applied for another US visa and was initially refused. I applied again and was eventually granted a visa. In September 1999 I attended my friend's wedding in Florida.

Impact on Education

98. Growing up I went to an ordinary infant school. There was a dinner lady there who would make me stand up for an hour or so at a time just to cause bleeds in my ankles. Some people are strange that way. The school knew that I had haemophilia.
99. In 1978 my mum was [GRO-C] It was a tricky time for us as my dad [GRO-C] [GRO-C] Consequently, I had to go and live out in the countryside with my grandmother.
100. I went to a school in my grandmother's village, which was a couple of years below my schooling level. I was out there for six months. When I came back to Burton-on-Trent in 1980 it was time for me to join secondary school, but I was behind as a consequence of attending the school in the countryside that was below my schooling level. I was always playing catch up.
101. I settled into secondary school reasonably well. However, the school did insist that at break times I was not allowed to go out with the other kids. I had to stay indoors. My school life was not too bad but I got stick for being a haemophiliac. I am also blind in one eye and got a bit of stick for that.
102. I did reasonably well at school. I undertook woodwork and metal work classes and never had any injuries whatsoever; whereas I witnessed others put drills through their hands.
103. In 1985 the local newspaper published a front-page story on me. I display here a copy of the newspaper. A segment of the front page story states, "*The boy has to be wrapped in cotton wool.*"
104. I remember going to school the following day and others said they saw me on the newspaper. It was not a wise move for the newspaper to publish this article about me.

Impact on Work

105. I left school in May 1985. The first thing I did was go to a training centre in Leicester for three months, learning electronics assembly. Whilst there I did other courses including factory work, but I was primarily there to learn electronic assembly.
106. Not a great deal happened during my time at the training centre in Leicester; I had a couple of bleeds where I had to go to the Leicester Royal Infirmary and have some factor VIII treatment. At this time I was totally unaware that I was HIV positive. I finished at the training centre in September.
107. In December 1985 I managed to get onto a youth training scheme at YTS here in Burton and remained on it until April 1988. I was with people my own age. Some were learning electronics, others office work. We were from different walks of life. It was pretty good.
108. Recalling paragraphs 21-22, in September 1986 I was diagnosed with HIV. The following year in 1987 I was at work at the youth training scheme in Burton. I was talking to a friend and mentioned to him that I was HIV positive. He kind of looked at me and said, *"You look fine"* and I said, *"I know but that is what I've been told"*.
109. What I did not realise is that one of the bosses had overheard me. My boss called me to one side and said, *"I overheard what you said, I think it would be in the best interest if we told everybody"*. He knew nothing about haemophilia or HIV. I do not think it was a wise move.
110. One day my boss called everyone on the youth training scheme into the conference room. There were about 150 people in there. He stood up and told everybody about my HIV status. He named me and never gave me a chance to speak.
111. Upon completing YTS in April 1988 I received a placement at a local electronics company called DAC in Burton-on-Trent.
112. On my first day at DAC, one of my bosses called me in and said, *"We've got a bit of worrying news because we've found out that you are HIV positive."* They had found out a week before. I do not know how they found out; perhaps someone at the pool club had told them, but I am not certain.
113. Following this I continued to work for DAC. My colleagues were predominantly women and two other men. The women did not seem to treat me any differently, certainly not to my face anyway. I went in day-by-day and did my work.
114. After six months at DAC I was told I had to leave. The staff there said, *"Either he goes or we go."* I was eased out the door and that was it.

115. I have never worked since. My not working is in large part due to the stigma associated with my HIV status.

Financial Effects

116. I am on Employment Support Allowance (ESA) because I am not working and have not worked since I was dismissed by DAC in 1988. I do not have the financial burden of having children.
117. I am not rich, so life is up and down. Some months are more difficult than others in terms of paying household bills and there is no excess of wealth in the family. There is not a lot of money.
118. When I was given money in the early 1990s, many people at that time thought they did not have long to live, so let's spend it, but I did not think that way. I invested mine.
119. Three and a half years ago I talked to my mum about buying our council house with the Right to Buy scheme. I had a figure in my head, hoping they let us have it for £40,000. I thought they would be fools not to allow it.

Treatment/Care/Support

120. I have not had any counselling or psychological support.
121. 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.

Financial Assistance

122. I cannot remember how I became aware of the schemes, but I believe it was through the Haemophilia Society in the early 1990s.
123. I received assistance from the MacFarlane Trust, having made contact with them somewhere between 1990-1993. I do not remember the exact amount received from the MacFarlane Trust.
124. I now receive assistance from the England Infected Blood Support Scheme (EIBSS). The amount is £1600 per month; I do not know if it is index linked.
125. I received an ex-gratia payment of £20,000.
126. The process of applying to the MacFarlane Trust involved tracing down my medical records to provide proof of eligibility. I wrote a letter to Frank Hill at Birmingham Children's University.

127. The process of applying to EIBSS involved filling out a form of 4-5 pages. I entered all my details including what income support I am on.
128. I did not have a lot of problems applying for and obtaining financial assistance. I did have difficulty finding documentation to demonstrate how I was infected.
129. Regarding any preconditions imposed by the MacFarlane Trust, I believe I may have had to sign to state that I would not claim in the future. I recall not initially agreeing to this as their mentality was accept or fight. I wanted to fight, but I went with the majority. I felt pressurised to accept.
130. My transfer from MacFarlane to EIBSS was straightforward. As mentioned above in paragraph 127, I received a 4-5 page form and did not have to provide any further documentation to demonstrate how I was infected as this was already recorded via the initial application to the MacFarlane Trust. There were no preconditions attached to my EIBSS application.
131. I suppose if I was married and had kids I would want more assistance, but I feel that I am in a lucky position of not having this financial burden. I feel that the system has got better. I know there are many people who complain about it. There has been some discontent that the MacFarlane Trust were not running the trust appropriately; there was talk of money being withheld which should have been given to deserving families.

Other Issues

132. My current GP is located at the [GRO-D] [GRO-D]. However, I am changing my GP because I am not happy with the care received there. My previous GP, Dr. Luft, was brilliant. My care went down after he retired.
133. In 2017 I injured my back. I went to Oxford and saw the physiotherapist there who said I would need to request local physiotherapy from my GP. I requested this from [GRO-D] [GRO-D] three times. The surgery advised they would refer me but I never heard back.
134. I injured my back again this year in 2018. This time Oxford wrote a letter to my GP telling them that I need physiotherapy [GRO-D] [GRO-D] finally referred me. It goes without saying that a haemophilic and HIV positive patient such as myself should not have to chase up a GP so many times for a much needed treatment.
135. Brighton University interviewed me on 16 April 2004 as part of the Haemophilia Life History Project. It was a one-day interview. The purpose of the project is for future generations – medical students in

particular – to learn about the Contaminated Blood Scandal and understand what myself and others went through. These stories are available at www.livingstories.org.uk.

136. Public speaking is something I have been doing since 1997. Pat Waine, a clinical nurse specialist writing a dissertation, came to me and asked if she could use me as a subject. She also asked if I would speak to medical staff at one of the hospitals. I took up her offer and talked about my experiences.
137. Since 1997 I have done four or five speaking engagements a year at various places around the country including Cardiff and at the John Radcliffe Hospital in Oxford. Sometimes I am phoned out of the blue with a speaking request. Public speaking is a good and fulfilling experience for me.
138. I am now on a peer review group that will start in February 2019. This involves travelling around the country to review quality standards at hospitals. I will go into the hospitals and look at their set-up and how they do certain things, specifically in regard to haemophilia treatment.

Statement of Truth

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

Signed GRO-C

Dated 2 May 2019