Witness Name: GRO-B
Statement No:WITN1137001
Exhibits: WITN1137002-03
Dated: November 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B of GRO-B West Yorkshire, GRO-B My date of birth is GRO-B 1968. I live at the above address with my wife GRO-B and my 16 year old son GRO-B I work full-time as a Shift Engineer for GRO-B

2. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records, the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How infected

3. Shortly after I was born at Huddersfield Royal Infirmary, I was diagnosed with mild Haemophilia A.

4. Throughout my childhood, if I suffered any minor injuries, I would have to attend hospital due to concerns about my haemophilia and I was frequently in and out of hospital. To start with, when deemed necessary, I was treated with cryoprecipitate. Later on, when I was about 10 years old in 1978/1979, I was treated with Factor VIII blood products. I remember this because I moved closer to the hospital at around this age and I remember this was when my treatment with Factor VIII began.

5. I exhibit at "**WITN1137002**" a list of the blood products which I have received, which has been provided by the UK Haemophilia Database. However, as can be seen from the chronology of my medical records, I received factor VIII on more occasions than have been recorded on the database.

6. To start with, I received treatment for my Haemophilia at Huddersfield Royal Infirmary, under the care of Dr Alan M Barlow, Consultant Haematologist and Pathologist. I believe his middle name may have been Michael.

7. At Huddersfield Royal Infirmary, I was also treated by a Mr Tam Cruz, Consultant Haematologist, Mr S Jalihal, Consultant Haematologist, Mary Morgan, Consultant Haematologist, who went to practice in Austria, and a Dr Winter or Winters, a locum Consultant Haematologist I believe, who was very involved with Haemophilia care in the 80's and 90's. I was also treated with factor on a number of occasions by an N A Boyle, who I believe was a Consultant Paediatrician.

8. My treatment later transferred to Bradford Royal Infirmary, where I was initially treated by a Dr Parapia, Consultant Haematologist, who has now retired. I am now treated by Sam Ackroyd, Consultant Haematologist. I have seen other doctors for my HIV and Hepatitis C care.

9. At one point, my parents went to a meeting with a Dr Sweetman, who dealt with paediatric care at the Princess Royal Infirmary in Huddersfield. He was

keen for all the "special children", as he called us, to go to the Treloar School. However, my parents decided that I should stay at home.

10. I believe I was given infected blood products between 1970 and 1984. I believe I was infected with Hepatitis B in around 1979, as this is what Dr Barlow told me when I received my diagnosis.

11. I had a bad anaphylactic reaction to Factor VIII just after Christmas 1980. When Dr Parapia looked at my medical records for the litigation I pursued in the US, he said that one of the major viruses probably took up residency in my body at this point.

12. I was a child when I received blood products which turned out to be infected. My parents were not informed that there were any risks associated with me receiving blood products. They were not even told when my treatment changed from cryoprecipitate to Factor VIII.

13. I remember going to Huddersfield Royal Infirmary with an ankle bleed and being given cryoprecipitate, which came in frozen blood bags which were defrosted and drawn up. The next time I attended the Huddersfield Royal Infirmary I was treated with a product which was drawn up from a small vile, which was Factor VIII.

14. In between the two treatments, there was no discussion whatsoever with my parents or I about changing my Haemophilia treatment. I feel that our freedom of choice was taken away from us. I strongly believe that if my parents had known about the risks associated with Factor VIII, they would have ensured that I was not treated with it.

15. As a result of being given blood products, I was infected with HIV, Hepatitis C and Hepatitis B.

16. My parents were first informed of my infection with Hepatitis B and HIV in the early 80's. They were told by Dr Barlow, who said that I had probably been

infected in around 1979. I have been told by my parents that they decided not to tell me about my diagnoses straightaway, as they wanted to wait until I had done my "O" levels and got in to work before telling me.

17. I remember just after I had done my first year exams for my apprenticeship, when I was around 17 years old, a letter arrived on a Friday which my parents wanted to discuss with me on a Sunday.

18. I remember a school friend telephoned me on the Sunday, and my Dad told me to put the phone down and to tell him I'd ring him back. I thought I was in trouble as it was a strange thing for my Dad to say. My parents then told me that I had been given Factor VIII from America which had been infected with the AIDS virus. I remember feeling dazed and asking "how long have I got?"

19. My parents said that Dr Barlow had told them that the virus had an incubation period of 10 years and I was thought to have had the virus for a number of years. They said that if I got to 22, I might be ok and that treatments were being worked on. I was in tears and wanted the ground to swallow me up.

20. It was from this discussion with my parents that I found out that I had HIV and Hepatitis B.

21. My parents told me that Dr Barlow wanted to see me to discuss my infections, and so I went to see him and Mary Morgan. I remember it was a Monday and they were both gowned up and wearing surgical masks and gloves and I wondered whether I would be undergoing some kind of examination or procedure, as they wouldn't normally be dressed like this.

22. They were both very matter of fact and told me that I had been infected with the AIDS virus. They had no bedside manner whatsoever. These were people who had looked after me for years and had previously been fine, understanding and caring.

23. I was advised not to have any physical relationships, because of the risk of transmitting HIV. This was a very difficult thing for a 17 year old man to be told. I was also told not to get emotionally attached to girls, as I would be

setting myself up for heartache and I would be leaving someone behind if we fell in love.

24. I was also told that it was probably best not to pay in to a pension scheme, as it was unlikely I would make it to pension age.

25. I was told that I didn't have to work if I didn't want to, as I was a "lost cause" and there was no point. I remember specifically being told not to make any plans for the future. I was told not to drink too much and to live life to the full.

26. At that age, most 17 year olds are finding out about alcohol and what it can do and the normal sociable thing was to have a pint with your mates on a Friday, but I was unable to.

27. Dr Barlow told me that he thought the Government would give my parents money for my funeral. I remember asking whether they would need that soon and Dr Barlow saying "probably sooner rather than later". I could only think about how upset my mum would be.

28. I was told by Dr Barlow that I would probably have about 2 years left to live. I didn't expect to see my 21st birthday or to get a key to my own house.

29. In terms of daily practicalities of living with the infections, I was told not to share toothbrushes or bladed razors. I was living at home with my parents at the time and we had two bathroom cabinets, so I took over one. This wasn't a particular problem, but could have been if I had been living in different circumstances, such as in a dormitory or at University.

30. In those days, as the internet didn't exist, I just went on what I was told by the medical professionals.

31. I had only just started my life and was making plans for the future and then I was told I was going to be wasting my time. I felt like I had a lot of questions, but no one had the answers. I felt extremely frightened about the future.

32. I had been made to feel worthless at 17 and as if I had no life ahead of me. The information just didn't compute in my brain.

33. At that time, the AZT drug was available to treat patients with HIV, but I was told that I didn't warrant starting treatment straightaway, as my condition wasn't viral.

34. I remember after this meeting with Dr Barlow and Mary Morgan sitting outside crying and thinking that there should be something that they could do. I had gone on my own to this appointment, as I was a young man and I didn't want my parents knowing about my private life.

35. When I went home and told my parents about the appointment my Dad lost his mind, when he heard what Dr Barlow had said about the cost of my funeral. My dad went to the hospital, but I'm not sure what happened.

36. Soon after my appointment with Dr Barlow, my GP, a Dr GRO-B came to see my parents and I at home. He was a good GP, but with a very poor bedside manner. He told me that he couldn't make things better, but told me to look after myself, to have a good diet, to exercise and to keep my head straight. He told me the worst thing I would do was worry. He encouraged me to move forward. I told him that Dr Barlow had told me not to work, but Dr GRO-B said to do what I wanted to do. He told me that things wouldn't be like this forever, I think he meant the outlook wouldn't always be so grim.

37. Soon after I was told of my diagnoses, Dr Barlow called my Mum to say that he had seen me with a girl near the hospital, who was my girlfriend at the time. Dr Barlow said to my Mum that he hoped that I wasn't sleeping with her. My Mum told him that it was none of his business. I was horrified at such intrusive episodes.

38. After being diagnosed with HIV I went on a health kick. I was in very good shape physically and was exercising a lot, but mentally I felt dire, because I thought it was the end for me.

39. I would say that it took me about 6 months for my diagnoses to sink in. I was numb after being told. I became like a robot. I would just go to work and come home. It was an existence not a life. I was waiting for a flash of light

40. Once I was told of my infections, I felt as if the medical profession didn't know what to do with people like me. It was as if they were ashamed or embarrassed and they didn't want to deal with us publically.

41. Before I was told of my infections I felt I was treated well. However, after I was told about my infections, the medical staff started wearing rubber gloves and masks to deal with me. At the time, I was told that this was protocol, but this wasn't something they had done before. I was made to feel odd and different as a teenager and ushered in to a side room. This wasn't something which bothered me at the time, but as I have thought about it since, I feel I was dealt with poorly.

42. In the early 90's my care transferred to Bradford Royal Infirmary. I had asked on a number of occasions whether I had been infected with Hepatitis C and I was told by Dr Parapia that I hadn't been.

43. I asked about this on three occasions. Firstly, because we had a letter from the Macfarlane Trust to say that a number of haemophiliacs had been found to have Hepatitis C and that we should discuss this with our haemophilia centres. I went to Dr Parapia after I received this letter and he told me that I didn't have Hepatitis C. We got a similar letter from the Haemophilia Society, which prompted me to ask Dr Parapia again about whether I had Hepatitis C and again, I was told that I didn't have it.

44. Following this, my close friend, Paul **GRO-B** who had also contracted HIV from contaminated blood products and had been in the same boat as me, was told that he had Hepatitis C and was very upset about it. This prompted me to ask Dr Parapia again as to whether I had Hepatitis C and again I was told that I didn't.

45. I attended a standard appointment with Dr Parapia, Consultant Haematologist in 1995. I remember that my file was green and I saw Hepatitis C was written on my file in big red letters. I asked Dr Parapia about it and he became very

defensive and said that they had already told me that I had it. I made it clear to him that I had never been told I had Hepatitis C and I became very upset and angry.

46. Dr Parapia began saying things like "if you're going to be like that we'll have to think about who is going to treat you in the future". He also called nurses in to witness our conversation.

47. I believe that I saw in my medical records that I first tested positive for Hepatitis C in 1983/4. However, I did not find out about the infection until 1995. In 1983/84 I believe I was tested for Hepatitis C without my knowledge and consent.

48. I exhibit at "**WITN1137003**" an extract from my medical records which refers to me testing positive for the Hepatitis C antibody in July 1992.

49. Whenever I asked about treatment for my Hepatitis C there was a great deal of reluctance from Dr Parapia to put me on any treatment due to the cost of triple therapy for Hepatitis C.

50. After I became aware of my Hepatitis C infection, I was spoken to by Dr Parapia about how to manage it. I was told that I could not pass Hepatitis C on sexually or by touching another person. I was advised to limit the amount of alcohol I drunk.

51. I was told not to worry about the infection as lots of treatments were becoming available. I was told that at worst my liver would enlarge. I don't feel like I was given any credible information.

52. I recall that Dr Parapia did not want to explain or be questioned about my Hepatitis C diagnosis. If I raised questions, nurses would be called in and my questions went unanswered.

53. I remember talking to a Dr McCheetah or McKeetah about my Hepatitis C and he told me that I would live for another 10 years if I was lucky. This really

upset me and I told him that I wanted to speak to somebody senior to him. I asked Dr Parapia about this doctor's comments. Dr Parapia told me not to listen to him. I got really frustrated about the lack of information I was being given and I told Dr Parapia that I wished somebody would have the guts to tell me how poorly I was. When I got angry, this is when Dr Parapia finally discussed treatment with me.

54. I later found out that Hepatitis C can be worse than HIV, and that if someone has both infections, they can advance one another with terrible consequences.

55. I should have been informed of my Hepatitis C diagnosis as soon as I tested positive, instead of it being left for over a decade and it only being discovered due to my own enquiries. At this point I was in a long term relationship with my wife GRO-B, and we were thinking about getting married. I was angry that I wasn't made aware of the risk I potentially posed.

56. I felt the way in which I found out about my Hepatitis C diagnosis was very haphazard. It appeared as though the infection was a secret that the doctors didn't want people to know about. However, they were unable to keep it a secret for long, because people wanted explanations for why their loved ones were dying.

57. I felt the hospital staff dealt with me in a very dismissive manner whenever I asked questions about my diagnoses.

58. If I had been made aware of my diagnoses at an earlier date, I could have made plans and prepared for my life, with knowledge of my infections. But I was unable to do so, as they kept my diagnoses from me.

59. I think my parents did what they thought was right at the time, telling me about my diagnoses after my exams and once I was in an apprenticeship. I scrapped through my "o" levels. I think if my parents had not had the upset of finding out about my infections, they would have been more on my case about studying and I would have got better exam results. Because they weren't, I did

the bare minimum, as I didn't feel they were important, but later in life I realised that this was a missed opportunity. My outlook on academia is different now.

60. I have caught up on my studies in later years by studying vocational exams, but I wish my parents had been more on my back when I was younger.

61. I think that when I was told that I had been infected by contaminated blood products, the doctors should have started at the beginning. They should have explained that I had been treated with factor from America, that somebody had messed up and explained my options to me going forwards. This would have been a much better way of dealing with the situation, rather than just telling me what I shouldn't do, that I was a lost cause and to find my path.

62. The way in which I was told of my Hepatitis C diagnosis was flippant, 10 years after the medical professionals were aware of it.

63. I think there should have been some kind of information and list of recommendations/an aide memoire given to me on what I could do to make my life more comfortable.

64. I didn't receive any information about my health until 1992, 5 to 6 years after I had received my HIV/Hepatitis B diagnoses. This was at Bradford Royal Infirmary, which was much better in terms of communication. There I was told that treatments were being worked on which could help me. I felt more centred and hopeful once my care transferred to Bradford Royal Infirmary.

65. By the time I found out about the implications of my infections, I had already been in 3 physical relationships. After being told about my infections, I had to tell my former partners and to encourage them to get checked. I managed to contact 2 of them, but I was unable to contact the third as she had left the country. As far as I am aware, none of them have become infected. However, informing my former partners was an extremely difficult thing to do.

Section 3. Other Infections

66. I have been tested for Hepatitis E and Hepatitis G. Although these tests came back as negative, I do not trust these results as I am yet to see them for myself. I have pushed to see the test results, but Paul GRO-D who works in haemophilia/HIV care at the GRO-B won't let me see the results.

67. I have reason to believe that I have been infected with vCJD. I was informed in around 2003/4 that I was treated with factor which came from a British donor who was found to have vCJD in his biopsy. This man did not die from vCJD. This is another worry for me and I am waiting, like many others, for a test for this to become available. When I questioned Dr GRO-D, Consultant Haematologist at the Bradford Royal Infirmary about this he simply said that most people who have eaten British Beef between 1988- 1995 will have it. The test for this can only be undertaken during an autopsy, so I am unable to get tested for this at present. When I asked if haemophiliacs will be at the top of the list to get tested when a new method becomes available, Dr Ackroyd said that he couldn't confirm this.

68. There is evidence to suggest that haemophiliacs treated with blood from cadavers from the Russian morgues have also contracted West Nile Virus and the Parvovirus. As such, I suspect that I have also contracted these. I have asked to be tested for both West Nile Virus and the Parvovirus, but have been informed that I will not be tested for these under any circumstances.

69. I probably have a whole list of viruses that haven't even got names yet. The blood products I received came from people who could have been doing anything to themselves and one another.

Section 4. Consent

70. Prior to being informed of my Hepatitis C infection, I was tested without my knowledge or consent. There is a letter in my medical records stating that I

had been tested and was positive. There was mention in another document that I had been re-tested and the source of the infection was American Factor VIII blood products. My parents and I were not aware of these tests.

71. I have reason to believe that tests were done on me for the purpose of research.

72. Under Dr Barlow's care, I had spinal taps on a number of occasions, during which bone marrow samples were taken. When I asked why these were being done, I was told that I may be at risk of meningitis, due to my weakened immune system and they needed to take these samples to test them. Only one instance of this testing is mentioned in my medical records, but I had many spinal taps done at Huddersfield Royal Infirmary.

73. I have written to the Huddersfield NHS Trust on three occasions about this, but I have never received a response. I'm aware that the Trust was busy at the time merging Hospitals, but I think they should have at least provided me with a response, even if it was to say that they didn't know the answer to my query.

74. Dr Barlow was also West Yorkshire's Chief Pathologist, and he worked on the Yorkshire Ripper murders. He regularly spoke about research projects he was doing. I believe that the tissue and blood that was taken from me whilst I was under his care has been stored somewhere and been used for research projects.

75. Further to this, I am of the opinion that I was deliberately infected with HIV and Hepatitis C. As a previously untreated patient, there was no need for me to receive Factor VIII. I have seen information that suggests that all centre managers were told that Factor VIII was infected and should be withdrawn. I believe that this was not done on costs grounds and instead the product was used to treat people like myself.

76. Conspiracy theorists suggest that haemophiliacs were used as biological weapons. If this was the case, then the effects of these infections were more

far-reaching than just making a 'mistake'. A 'mistake' cannot be made thousands of times, it would happen only once or twice. I believe that what happened to us was deliberate. I believe we were experimented on for some unknown reason.

77. Prior to being treated for any of my infections, I was subjected to months of what was called "cognitive behavioural therapy", which was instigated by Mary Morgan, Consultant Haematologist. I received this in a side room at the back of the pathology laboratory at the Huddersfield Royal Infirmary, on level 2 I believe. I was told that this was to monitor my brain functioning. I was told that if my brain functioning was slowing down then my HIV had progressed.

78. During this therapy I was required to complete jigsaws and various other tests like at a job interview, which were timed. The tests often involved patterns, shapes and sequences. I was asked to complete the tests on a weekly basis. I remember that one of the jigsaws was a hand and I had to put the fingers in the right order.

79. I was just a kid at that time. I was terrified of failing or slowing down, as I was led to believe that this would mean my infection was getting worse and this would mean the end for me. For my own mental wellbeing, I needed to pass the tests and work out how complete them in a shorter period of time every week.

80. Eventually, I became fed up with the tests and I began to question their validity. When I told the staff that I was no longer going to do the tests, they simply said "okay" and nothing more was said about it. At this point, I had already been completing the tests for over 12 months, on a weekly basis. These tests put me under a huge amount of strain and I suffered a significant amount of emotional trauma during this period, for which I was offered no counselling or support.

81. There is no mention of these tests in my medical records.

82. Looking back, I question how necessary these tests were and whether they could not have done a viral load test instead.

Section 5. Impact

83. Being infected by contaminated blood products and the way I have been treated over the years, has left me aggrieved to say the least. I remain angry and upset. Things are just as raw to me now as they were 30 years ago.

84. If I had 10 minutes in a room with the likes of Dr Barlow, who is now dead and Mary Morgan, who I believe is still alive, they would know what I think of them.

85. As part of the Hippocratic Oath, I believe doctors are meant to swear to be caring and deal with their patients to the best of their ability. However, I don't feel I have been treated like this by many of the doctors I have seen.

86. I have many emotional wounds that will not heal.

87. I have undergone traumatic treatment, which has left me with not only physical scars, such as peripheral neuropathy, but also deep emotional scars.

88. I am upset and feel that my emotions are more akin to mourning. I am in mourning for the life I could have had, the loss of friends and potential relationships.

89. Around 6 months after I was told of my diagnoses, I met an Irish girl called GRO-B who was perfect. We met at a concert and fell for each other. She was a breath of fresh air after receiving my diagnoses. We got involved in a serious relationship and we talked about getting married and having a future together. We were both besotted with one another. She was training to be a teacher and I told her that I would move to wherever she needed to go to do her training, so that we could be together. However, the dark cloud of my diagnoses always hung over me and I couldn't bring myself to tell her. I was

paranoid that if she found out about my infections she would end our relationship.

90. This is the only relationship I've had where I've felt totally loved, validated, needed and desired. We had a fantastic time together.

91. In the end, after around 18 months, I decided that I had no option but to break up with her, which I did. I went and told her that I had to stay in Huddersfield to work for my Dad.

92. This has been one of the worst losses of my life. The way we were together made me feel like I could get through anything with her by my side. I have tried to trace her since through Facebook and through my connections in Ireland, without success. I'm sure things will have worked out for her.

93. This decision still kills me now. For years I have wondered about the life we could have had together in Ireland, where my family are from.

94. After breaking up with GRO-B I wasn't bothered about relationships until I met my wife GRO-B

95. When I started receiving treatment from Bradford Royal infirmary, I was seen by a nurse called Pauline Sharp. She put me in touch with another patient called Paul GRO-B We were often in hospital together receiving treatment. We planned to "take on the world" together and agreed that we wouldn't "go" without putting up a fight. Paul passed away last year, which hit me very hard. Losing Paul is a wound which will never heal.

96. I have lost count of the number of friends who have passed away as a result of receiving infections from infected blood products. There used to be 12 of us receiving treatment together at GRO-B but now I am the only one left.

97. In one year alone I attended 12 funerals. I am upset at the loss that has happened to our community. It feels like a dark cloud hanging over us.

98. I also feel angry. I thought that after 30 years, my feelings would manifest themselves differently, but I just feel angry.

99. Some of the distress and upset from my infections stems from years of living in fear. Whenever I had an ache or pain I feared that my HIV had progressed into full-blown AIDS. I've always wanted to move forward with my life, but have felt like my infections were holding me back and that I was wasting my time. I have never known how long I have ahead of me.

100. I want to live a normal life and I try to not let my HIV infection affect my mental health. I don't want it to define me, but the first and last thing I do everyday is take medication, and this is a stark reminder of what I have and who I am now.

101. I worry about the future for my wife and my son.

102. The things that go through my head on a daily basis are odd and are not normal. I believe that these thoughts come from the years of living with my infections.

103. A further mental effect of my infections is a complete loss of faith in doctors. When I was told of my diagnoses I had to go on what the doctors told me, but since 1996 I have had access to the internet. Since then, I have questioned and researched everything myself. I will no longer let anyone put anything in my body without researching what it is and ensuring it is safe. This includes medication and needles.

104. Psychologically, my emotions are stunted. I feel that my desires are rather childish. I still think and feel like a 17 year old.

105. When I was told I had 2 years left to live in my late teens, it was like a weight around my neck, nothing mattered to me.

106. I treated women very badly around the time that I found out about my HIV infection. I went through relationships in weeks and months. I had a spell of about 6 or 7 short relationships, which were physical. I was very clinical and cold with my girlfriends. There were terrifying adverts at that time about AIDS showing people in chains. People were being extra careful with contraception and "double protecting" themselves with contraception and showering afterwards.

107. I imagine that my wife would describe me as very solitary. I am like this now as I feel it protects me from getting hurt and being subject to scrutiny. I feel as if I have had enough scrutiny from doctors over the years and I don't want any more of it in my personal life.

108. I don't feel comfortable in my own skin and never have since I received my diagnoses. I feel as if my body belongs to somebody else. I feel as if I watch myself like a voyeur.

109. My confidence took a massive dent when I was told of my infections.

110. I keep expecting somebody to come and make things better for me, but no-body will.

111. When I was told of my HIV and Hepatitis B diagnoses, it was a time when I was meant to be finding my place in the world and I feel as if I never have. I feel as if I'm a stone shifting in water from one trauma to the next.

112. I feel as if I'm never destined to be happy, no matter what I do.

113. My wife GRO-B thinks I have anger issues, which I don't think I have. However, to placate her, I attended some anger management sessions some time ago. I sat there and listened. I didn't relate to the issues the other participants had and I didn't feel it was the place for me.

114. I was told in 1997 that I had probably self cleared Hepatitis B by Pauline Sharp at Bradford Royal Infirmary. I received 2 parts of a 3 part innoculation.

115. With regards to the physical effects of being infected with HIV and Hepatitis C, these infections manifest in a couple of different ways.

116. I have a scarred liver as a result of my Hepatitis C.

117. My skin is thin in a lot of areas and often cracks and bleeds, due to the retro-viral medication I take. It becomes very itchy, sore and raw in areas. In the winter, the skin on my joints and fingers splits. I have to wear two pairs of gloves at work for this and the pain can slow me down at work.

118. Because of my skin problems, I have to avoid any scented products and I use traditional soap most of the time. I have a repeat prescription from the GP for steroidal cream, which is an anti-itching type cream and is very effective.

119. As a result of the Hepatitis C, I also have hives all over my body, which are like mosquito bites.

120. The co-infections have also made my teeth and nails brittle, so I regularly require dental treatment. My teeth become brittle and break or fall out. I have had to have a lot of teeth extracted, including the grinding teeth behind my canines.

121. I used to attend the dental clinic at the Bradford Royal Infirmary until 18 months ago for dental treatment, where my treatment was free of charge. However, my care has now transferred to the Princess Royal Hospital in Huddersfield, where an extraction costs £90. I have required 3 extractions in the past 18 months.

122. Due to the co-infection and the long term use of the retro-viral medication I take, I have also been told that my bones are deteriorating and crumbling, particularly my hips. I have had 1 hip replaced. The bones at the top of my spine and bottom of my pelvis are also crumbling. I take a very strong anti-inflammatory on a daily basis to help with my symptoms.

123. I suffer from bad hair loss. I used to have thick brown hair, but due to it falling out, I have to keep it short now.

124. Episodes of bleeding are minimal now and they have to be fairly serious for me to require hospital intervention.

125. As a result of my co-infections, I suffer from constant bodily and joint pain and fatigue, which is very bad. I have abused alcohol and prescription pain killers to cope with the pain in the past, something which psychologists call "crutches".

126. I chose painkillers as I had unrestricted access to very strong medication, many opiate based, which numbed the physical pain as well as the emotional pain to a degree. When the tablets didn't work, I found lager and then vodka were more effective.

127. I managed to work and live without my infections going noticed for a few years. When my wife and I were trying to conceive, I went cold turkey.

128. I didn't go back to abusing alcohol and drugs after this.

129. I also experience brain fog due to my co-infections. This is where my diction, vocabulary and speech goes. The older I get, the worse this seems to get and I lose the thread of speech and conversations, which is very frustrating.

130. My HIV also causes night sweats, constant diarrhoea, oral and auditory bleeding,

131. I have HCV Genotype 1, which is inflammation of the liver due to Hepatitis C. My liver is heavily scarred and damaged in two areas. I have had a number of tests on this, but am yet to undergo a biopsy.

132. In 1991, I was told by the Bradford Royal Infirmary that I had Hepatitis A but had probably self-cleared the infection, as I had Hepatitis A antibodies.

133. In 2003, whilst on holiday in Spain with my wife and family, I developed pneumonia and was admitted to the Intensive Care unit at the Son du Retta University Hospital, Palma. There, I saw some top specialists who discussed my HIV and Hepatitis C with me. They told me that I had full blown AIDS, but that this wasn't the death sentence that it once was.

134. When I was first given my HIV diagnosis, I was told that I didn't need to take medication, but that it would be available for me if I wanted to take it in the future. When I returned from Spain, I was vey thin and unwell and I was told by Dr Parapia that I needed to start taking the retro-viral medication.

135. I started treatment for my HIV infection in 2004. To start with I was prescribed 2 lots of medication, Atripla and a broad based antibiotic. I had to take 30 tablets a day. At that time, the doctors were trying to move away from AZT treatment, which they had realised made things worse for the co-infected and gave then dreadful side effects.

136. I stayed on that medication until I changed to Evipleron, which I am still on now. This is just 1 tablet a day.

137. In 2005, I started combination therapy to treat Hepatitis C at the Haemophilia Centre at Leeds Royal Infirmary. This treatment lasted for 12 months, it was very traumatic and I suffered from a range of symptoms.

138. The treatment involved being injected in my stomach with Interferon once a week, and I would also have to also have to take 10 Ribavirin tablets a day.

139. I suffered from drastic weight loss (15 kg in one week) and a great deal of skin irritation. The injections in my stomach, left my skin sore and bruised, and I had welts under my skin which I would scratch until my skin was raw.

140. I also suffered from extreme diarrhoea, nausea, vomiting, loss of libido, hair loss and loss of appetite. I also had aches and pains, particularly in my joints.

141. I had a second round of this treatment in 2013. Again I had interferon injected in to my stomach once a week, but the tablets reduced to 4 a day with the second round of treatment.

142. With the 2013 treatment, I had to take the tablets with a certain amount of fat. I do not tolerate fat very well, so it was fairly difficult to find a diet that worked with the medication. You could have some vile tasting milkshakes. I ended up having 2 tiramisus twice a day to metabolize the fat. Again I lost 15kg in weight and suffered the same symptoms as before.

143. Following the second round of treatment, I was informed that I had cleared my Hepatitis C infection.

144. When I was told this, I thought I would be doing cartwheels, but in my mind I thought it was one less thing to worry about. I had had 15 months without alcohol, so I just wanted a drink.

145. As a result of the combination therapy I have been left with peripheral neuropathy from the damage done to my peripheral nerves. This can result in symptoms of weakness, numbness, pain, tingling, burning, stabbing and shooting pains in my hands and feet. This is usually treated with Gabapentin, but this medication did not work for me at all. It resulted in me having violent sickness, diarrhoea and hives. I also suffered from very bad numbness.

146. I now use a chilli pepper ointment which stimulates the nerve endings in my feet and hands. This is effective, but difficult to use. It also means that I have fewer tablets to take.

147. As a result of the peripheral neuropathy, I now struggle to grip things. I use arthritic cutlery which has big handles. At work, I have to use spanners, but struggle to grip these. I put electric tape on my spanner to make it easier for me to grip. I also suffer with cold feet. Even in the less cold months I wear 3 pairs of socks, as my feet can feel like blocks of ice. I also have to wear thermal long johns and vests.

148. Even when we had the heatwave in 2018 and the temperature is in the 70's, my external temperature is always cold.

149. I have had an issue with lack of sensation in my hands and feet due to the peripheral neuropathy since approximately February 2014. I am unable to feel my fingertips. I could bite them and not feel it. I burn myself a lot, but don't realise and only become aware that my skin is burning when I smell the burning. I recently suffered third degree burns from burning myself on the hob. This is healing and there has been talk of me needing a skin graft, but I am hoping to avoid this.

150. When treatment for my Hepatitis C was being discussed, I lived in Huddersfield, but travelled to Bradford for my care, as there is not a Haemophilia Centre in Huddersfield. Huddersfield NHS Trust pays for my care in Bradford, but I was told that it was not possible for me to get funding to be treated for my Hepatitis C in Bradford, so I had to travel to Leeds for it.

151. I found out after I started the treatment for my Hepatitis C that it was being funded by a drug-company and was being monitored. I was not informed of this prior to starting the treatment and had not consented to this.

152. I discovered this when a Consultant Histologist called me 4/5 months after the treatment to inform me that the first round had failed. I was told that the drug-company were happy to pay for a second round, but I refused due to being unwell and I was upset that this had previously been hidden from me.

153. I felt as though we were being treated like lab-rats. If I had been told in the first place that the treatment was a trial for a drug-company, I would have thought twice about taking part.

154. After several years, I was told that another drug-company would fund my second round of Hepatitis C treatment if I wished to try it. I agreed to this, as they had asked for permission and consulted me on the details.

155. At one stage, it was recommended that I start taking the drug Interferon. However, from my own research, I discovered a paper in the Lancet which talked about Interferon accelerating HIV to the next level, and how you could die from HIV or Hepatitis C or both due to Interferon, which scared me, so I decided not to take it.

156. Doctors seem to think that we are stupid, but after having dealt with the infections for years, our community has wised up. Doctors used to have the approach of telling me what to do, but when I told them that I wished to undertake my own research before taking their advice, they were very taken aback. Dr Parapria was very abrasive when I told him about the article in the Lancet. I felt as if he knew secrets.

157. Since I found out about my diagnoses, my approach to medical treatment has been that if I'm in any doubt about a particular treatment, to do nothing.

158. I saw my good friend Paul GRO-B and his wife Dawn suffer the side effects of Interferon and I was glad that I wasn't on it at the time.

159. The retroviral medication I take causes me to suffer from very bad nausea, night sweats and vivid nightmares, which I have a few times a week. In the nightmares, I am sat next to a fire on a beach and I can hear people running around behind me. When I try to look at them I see that they don't have faces.

160. The psychologists I have seen think that the nightmares are a result of trauma from treatment.

161. The retro-viral medication is a pink colour, which comes out of my skin and stains my bed sheets. You can see where I have been lying.

162. The roof of my mouth, the insides of my cheeks and under my tongue are always sore and red. My glands also feel constantly up and hard.

163. I suffer from nausea due to my retro-viral medication and I am unable to tolerate dairy whilst taking this medication. I am violently sick if I have dairy

whilst taking the medication. I therefore have to have UHT milk in my tea. I used to like tea, but as the taste isn't the same now I only have a couple a week.

164. When brushing my teeth in the morning, this makes me very nauseous and I end up dry heaving for around 5-10 minutes every morning. This makes my diaphragm very sore.

165. I am a maintenance technician in a Mill and I sometimes work 50-60 hours a week, with some night shifts.

166. GRO-B
GRO-B
GRO-B

167. My job involves maintaining the machinery, such as the pumps, motors, gearboxes and pipework. I regularly do welding and make machine parts.

168. My manual job, which can involve long hours, coupled with the chronic fatigue I suffer, has a big impact on me and means I often wake up still tired.

169. I try to remain active and continue working, but I suffer from a series of aches and pains. I cannot account for their causes, but I know these cannot all be due to being on my feet at work.

170. I had my hip replaced a few years ago. This has still not healed properly and I get a lot of pain from it, but I'm not sure why.

171. Despite my aches and pains I have continued to work. This is not just for financial reasons. I want to set a good example for my son, and moving forward gives me a sense of achievement that I would not get from doing nothing.

172. I try to be a better person and learn new things, by doing courses. I'm not sure how long I'll be able to keep doing this, but I intend to continue doing so while I still can. My parents instilled this in me.

173. My parents always encouraged me to try to live a normal life and maintain a positive attitude. They didn't want my haemophilia to take over my life. They arranged for me to join the Scouts and I travelled all over the world with them and got to do rock-climbing, fishing and other outdoor activities as a kid. I am still involved with the Scouts today.

174. As a result of my infections, I am a very private and guarded person. I do not like to discuss my past or the experiences that I have been through as many people are still scared of the unknown and stigmatise HIV and Hepatitis C. If you say 'HIV' or 'Hepatitis C' to someone they do not think that someone has been infected with a blood product, they think of a prostitutes, drug-users or homosexuals; they think of people at the skid-row end of society.

175. I have heard stories of people being subject to abuse and vandalism as a result of their infections. I do not want this for myself or my family, and I do not want jokes or comments to be made about me. This has stopped me from having relationships that I would have liked to pursue.

176. Apart from my solicitors and medical professionals, the only members of my family who know about my infections are my dad and my wife. My mum passed away a few years ago. My extended family are unaware of my infections. Only very few of my close friends know about my infections and those are friends that are in the same situation, who I have met through treatment or campaign groups.

177. Some of my oldest friends, who I have known for 40 years and consider good mates, do not know about my infections.

178. Although I am constantly meeting new people, particularly in my job, I do not feel comfortable making new friends, as I do not wish for people to question me.

179. The infections make me a fantastic liar, something which my psychologist described as a survival mechanism.

180. Neither my wife GRO-B not my son GRO-B are infected.

181. My wife is a hairdresser and has a very good business, I do not wish for her to have any repercussions as a result of the stigma associated with my infections.

182. She also has to be very guarded about what she says about me. She doesn't discuss my medical condition with anyone. I have not asked her not to, this is just an unspoken understanding.

183. My 16 year old son is unaware of my infections. He has recently done his GCSE's and started college. I don't want to tell him about my infections and traumatise him, but I will have to in the future.

184. He hears my wife and I talking about the Contaminated Blood Campaign and he asks questions about it.

185. It is not always easy hiding my symptoms from my son GRO-B He sees me having injections and I tell him it's for my blood which doesn't clot properly.

186. When I was younger, I did not understand the responsibility of being a parent with a raft of infections. I am now aware that one day I may have to leave him on his own or with his Mum. I want to prepare him for the adult world, which is what I'm doing at the moment, preparing him for a time when I may not be there to help him.

187. I find being guarded all the time very hard. I would like to be an open book, but my past has to be closely guarded. I have slipped up a few times in the past

with people, but not in a way which has been noticed. I have felt like I dodged a bullet on these occasions, as I haven't wanted to start explaining myself.

188. I am never sure how forward thinking people are and I don't know if they will not want to shake hands with me or will make jokes about my infections, so I think it's best not to tell people.

189. I know there is nothing for me to be embarrassed about, as I have done nothing wrong.

190. When I first found out about my diagnoses, this had a big impact on me socially as a 17 year old man.

191. Before I was told of my diagnoses, I used to be the life and soul of the party. However, everything changed after I found out about my infections. I decided to become the "grey man" and stay in the shadows. I decided I wouldn't be the loudest.

192. Huddersfield is a rugby town and people either support rugby league or union or both. On a Saturday or Sunday afternoon, people would get together at the local YMCA to watch matches. I used to go with my friends or parents. At that time I lived in an area called GRO-B which was only 2 miles from the YMCA, and so it was easy to get to. For my friends and I, it was the centre of our socialising at that time and we would get together to kick a rugby ball, go to gym, get a massage or have a sauna. I used to love going there.

193. However, after receiving my diagnoses of HIV and Hepatitis B, I was scared of going to the YMCA and people noticing any physical manifestations of my infections. I imagined someone saying that I had an AIDS spot if we were in the gym or sauna. I wasn't prepared to tell anyone about my infections.

194. Huddersfield is a smaller town and people used to go for big nights out in the larger towns nearby, such as Halifax, Leeds, Wakefield or Bradford. I stopped going on these big nights out.

195. My parents used to try and encourage me to go out with my friends, but I was petrified of being found out. Instead, I slept away these years.

196. My close mates knew that I had a blood disorder and used to say to me that they thought I'd be dead by now, because of the press coverage of haemophiliacs getting infected by blood products. I used to tell them that I had been lucky and missed it and made a joke out of it, but I felt dreadful inside.

197. I lost friendships as I stopped socialising. People will only ask you to go out so many times, before the phone stops ringing. In one way I was glad about people not bothering with me, so I could keep myself to myself, but in other ways, I was of course sad.

198. I still have some friends from that time, but my change in behaviour definitely impacted my circle of friends.

199. With hindsight, I look back and think that I should have carried on going out with my friends. However, I had been told that I was a lost cause and I believed that. I spent my time waiting for the inevitable, which I had been told was to come.

200. I didn't know whether I would die in my sleep or I would see a flash of bright light.

201. At the haemophilia centre I went to, people had gone full blown and were dropping like flies. I didn't want to be a skeletal zombie. I wanted to go out in a blaze of glory and thought about the best way to orchestrate my death.

202. How I could end the mental pain I was in was constantly on my mind. I suffered from physical and mental anxiety which crippled me and left me being unable to breathe at times.

203. I remember coming home one evening and breaking down to my Mum and saying to her that Dr Barlow had told me that I was a lost cause and that was how I felt.

204. My parents battled with the haemophilia medical staff. They met the haemophilia nurse Pauline Sharp at one point and told her about how I had been treated at Huddersfield Royal infirmary. Pauline suggested to them that I transfer my care to Bradford Royal infirmary where she worked, which they did. This was a good move as I met lots of people in the same position as me, whereas I had only met 2 at Huddersfield.

205. When I was in secondary school, and after my parents had been told of my HIV and Hepatitis C infections, they didn't encourage me to work hard at school, as they didn't think that I would be around for very long due to my infections. I therefore scraped through my "O" levels.

206. At 17/18, I was in the best physical condition I had ever been in, so I took up 6th form college. I felt as if I had not learnt enough and I wanted to learn more.

207. Although I missed a lot of school, I tried to make up for this later in life, as I felt I had not learnt enough. As such, I have continued my vocational training and attended GRO-B University in 2003/4, to complete a foundation degree in Woodland Management which I passed.

208. When I was younger I aspired to be a blacksmith or gamekeeper, but I could not find any jobs available when I was starting work. I managed to get an engineering apprenticeship and have always worked in the trade since then.

209. Working in a trade has provided me with a skill that enables me to always find work. I think working has also helped keep me sane. However, if I had not been infected, I would have preferred a different line of work.

210. I am a very good photographer and I was offered a job in New York in 1999. This job would have been doing design agency work and would have been very lucrative. I was unable to accept the job as they asked questions for health insurance purposes and I would have been required to disclose my conditions. This missed opportunity feels like another scar that has not healed.

211. I have also considered working for the Highways Agency. In 2010 I applied and passed the first round of applications, but was unlucky on the second round. In 2017, I applied again and made it through both rounds of applications. I was then asked for a full work and medical history, and my availability for a full medical examination. The induction criteria for this position is very strict and their employees must undertake blood tests and random Hepatitis C tests.

212. Although I was qualified for this position, I was unable to pursue my application as my medical condition prevented me from doing so. Also, if I were ever to have had an incident at work which resulted in me bleeding, I would have had to be honest about my medical condition.

213. In 2015, I applied for and was provisionally offered a position as a Deer Ranger for the Forestry Commission. Deer are my passion and I would have loved to work outdoors with them. I had two interviews for the role and was qualified for the position. I already possessed all of the necessary qualifications and kit. Unfortunately, you are also required to have a clear medical history for this position and I was therefore unable to pursue this role.

214. I no longer wish to work in trade. I have done so since I was 17 and working in a GRO-B mill is hard work. I feel that my body is not going to be able to do it for much longer.

215. Although I have always tried to work, there have been occasions were have been unable to do so due to my health. For example, when I returned from Spain and had pneumonia in 2003/4, I had to take a few weeks off work. At this point I was severely unwell and was taking 30 tablets a day. I would not have been able to adhere to the strict medication routine if I had been working.

216. There have also been periods of illness between contracts where I have had to take time off to put my health first. Although this has not been ideal financially, it has sometimes been necessary.

217. Over the years, I have also spent a considerable sum of money on travel to medical appointments and prescriptions due to my infections. It is a 42-mile round trip to Bradford Royal Infirmary, where I'm treated for my infections. In addition to the fuel costs, parking costs £2.10 per hour. I attend the Haemophilia Centre there every 3 months, and the Trinity Centre in Bradford 4/5 times a year.

218. However, during periods of illness or bleeding I will often have to attend the hospital every day of the week.

219. I pay for my prescriptions and require £35.20 worth of prescriptions every 6 weeks, due to issues relating to my infections.

220. My parents have lived with guilt and upset since I received my diagnoses.

221. My dad is still very distressed that I have a list of diseases that could kill me at any time. However, he tries to be positive about it and encourages me to be the same.

222. Regardless of their hurt and concern, my parents always tried to maintain a positive attitude to my infections and encouraged me to do the same. I believe that it is because of their support that I am still alive today.

223. I met my wife around 30 years ago, when I was 19 years old. Over the last 30 years she has had to endure the upset and concern that result from my infections, it has been tough for her.

224. It was quite a while before I discussed my infections with her and we waited to have a physical relationship. When our relationship became physical, we had to be very careful and guarded, which sometimes ruined the moment. This was something we had to deal with.

225. We were later told not to have children, which was a very upsetting for us. All of our friends were having children and due to my infections, we decided to

spend our money on travelling and nice things. However, we were not satisfied with our lives and longed to start a family.

226. Eventually, we decided to be very careful and tried for a baby. After trying for a while, I became concerned that the radiation from my treatment had left me infertile. However, after medical tests, we were informed that we were both fertile and my wife became pregnant with GRO-B after 2 years of trying to conceive.

227. We didn't try for more children. This is not something we have discussed, but I would have liked more children.

Section 6. Treatment/Care/Support

228. The only time I really feel as though my infections have precluded me from being treated, was in 1982 when I injured my ankle playing squash.

229. I was treated for this in Huddersfield, but my ankle wouldn't heal properly and I was therefore referred to a Professor GRO-D in Oxford. After seeing me on a few occasions, Professor GRO-D said that there was nothing he could to do help me.

230. My mother suspected that this was due to him finding out that I was infected. When my mum expressed her concern for me at one stage, there was talk of her possibly needing psychiatric help. My parents were very angry, disillusioned and hurt by this, after they had previously held the doctors in high esteem.

231. I understand that Mary Morgan from the Bradford Royal infirmary intervened and wrote Professor GRO-D a stern letter about his refusal to treat me, but nevertheless, I went without treatment and continued to limp for another 6 years.

232. Every time my parents attended the hospital in Oxford, they had to fight with the staff to treat me.

233. When I went to Bradford Royal Infirmary, they told me I needed an ankle synovectomy for my injury, which they sorted out quickly. I was in a lot of pain with my ankle up until this point.

234. I have to have my dental treatment in hospital at the Dental Infirmary, rather than at a normal high street dentist. Bradford Royal Infirmary will not fund my dental treatment, so I have to go to Huddersfield Royal Infirmary for this after being referred from Bradford. This involves additional travelling, but I do this to get the best treatment.

235. I don't mind this, as the hospitals are aware of my infections and it avoids me having to tell my life story. The hospital has my medical records and can consult Haematologists if need be.

236. I have had 8 rounds of fairly intensive psychological therapy over the last 10 years at The Trinity Centre, St Luke's, Bradford.

237. I am no longer able to have the counselling due to NHS budget cuts. I am now only eligible to attend a one off drop in appointment between 10am to 12pm on a weekday, which I am unable to attend as I'm at work.

238. I found the previous psychological treatment I received helped me a lot. If I were granted another 5 or 6 weeks worth of treatment, I would take it and I would break my back to get there.

239. Whilst undergoing psychological therapy, I was told that I was suffering from anxiety. I am anxious because I don't know what is going to happen to me in a few years; what the result of the 30 year campaign and the Public Inquiry will be and not wanting to leave my son.

240. I have been to my GP about my psychological symptoms. I have never been diagnosed with depression, always anxiety. I don't want to be diagnosed with depression; I would describe myself as more upset than depressed. I have never been prescribed medication for my anxiety, but I wouldn't want to be, as I feel like I take enough painkillers and viral medication to manage my HIV infection as it is.

241. The GUM (genito-urinary medicine) clinic at the Trinity centre, St Luke's, Bradford wants us all to be tested for PTSD, but I don't wish to be tested. I don't want to have another label attached to me.

242. When my wife and I were trying to conceive, we encountered a very obtuse and abrupt doctor, a Dr GRO-D who was based on the Haematology ward at Bradford Royal Infirmary who told us that "you people should not be breeding". However, we later received advice from Pauline Sharp at the Bradford Royal Infirmary, who told us that she would offer support and information if we wished to conceive. At this time we were offered counselling, however we did not accept the offer.

Section 7. Financial Assistance

243. In 2005, I received a Stage 1 payment from the Skipton Trust, which was an award of approximately £350. I was unable to claim Stage 2, which was a monthly payment and lump sum, because I was told that my liver was not sufficiently damaged to be eligible for such a payment. The caveat to this rule was that you could claim if you had any problems or suffered any diseases as a result of trauma from medical treatment. I claimed for Stage 2 in May 2018, due to my peripheral neuropathy.

244. The process of applying for financial assistance with the Skipton Trust was very difficult. I believe that the system was not fit for purpose and was incorrectly set up. The trust was set up to placate a number of people, but

did not work properly. They had very strict criteria for applying and there was no margin for anything being different to what was on the script.

245. For example, most people received the first stage payment from the Skipton Trust, but struggled to satisfy eligibility for the second stage. To be eligible you had to have lymphoma, cancer or be put on the list for a transplant. When I spoke to a member of staff there, they said that you basically had to "be on death's door" to receive a payment. This answer was fairly flippant, but true.

246. Every month since the late 1990s, I have also received a payment from the MacFarlane Trust. This started off at £275 a month and remained at this level for years. It then increased to £600 a month, at around the time of the Archer report and then after around 8-9 years it went up to £1060 a month. The base payments are now £1500 a month, which is means tested. If you are on benefits/ a low income people may qualify for discretionary top ups. There was also a £100 payment per child, which has now become means tested. This is now paid under the EIBSS, the English Infected Blood Support Scheme.

247. Since May 2018, I have started to receive payments of £1500 a month under the English Infected Blood Support Scheme (EIBSS), so what would have been the McFarlane Trust payment. I have not yet had enough involvement with them to comment on them, but I feel that they dealt with my claim for Peripheral Neuropathy very efficiently.

248. I applied to the Macfarlane trust for a grant for a new roof as my existing roof was old and damaged. As a result of this grant, I was able to have the roof properly insulated, something which I was very grateful for, as I now save money on heating my home.

249. The process of applying for financial assistance with the MacFarlane Trust was relatively simple under the old manager Martin Harvey .

250. Generally, whenever you needed assistance you could write to them or contact them by telephone. They had a book of guidelines of what you can claim for and the amount you can receive.

251. Another example of my experience with the MacFarlane Trust is when I required new doors due to our old front and back doors leaking. I called the Trust and they asked that I get several quotes from independent local suppliers for the work that needed doing. Once I provided the quotes, the Trust looked at whether the amount was within their monthly budget. If it was more, then they had a business meeting to discuss it further. When a decision was made they then sent you the money via a BACS payment and you sent them the receipt afterwards.

252. I have received payments from the MacFarlane Trust for a new boiler (£1,100), two new doors and a window (£2,000), a fire (£400) and a new bed (£400).

253. When Martin Harvey was in charge, if he approved a request, you would receive the money the same day. I felt that he cared about haemophiliacs and our lives. The woman who started after him, Jan Harvey, was a nightmare and made things much harder.

254. Once she started at the Macfarlane Trust, my friends and I learnt that Jan Harvey had had issues when working as the financial controller for Battersea Dogs Home and the Fireman's Benevolent fund.

255. When Jan Harvey took charge of the Macfarlane Trust, the criteria to claim for things became much harder. If you applied for a grant, she would send people to interview you and take photographs of your home, to prove what you needed the money for.

256. A lot of haemophiliacs can't function and have issues with alcohol and drugs. There used to be a man called GRO-D at the Macfarlane Trust, who was a social worker, who looked out for such people and who would help

them with things like applying for benefits and mobility cars. However, Jan Harvey got rid of him.

257. There was also a lady who helped people with mortgage applications and Jan Harvey also got rid of her.

258. The Macfarlane trust guidelines were in place so that if you suffered a trauma, there was money there to help you. However, Jan Harvey knocked this on the head, which was a real blow to those that used the Trust.

259. The Macfarlane trust used to be based in a little office, but when she took over from Martin Harvey, she moved them to Alliance House in London and took on a massive lease. She used the money which could have been used for haemophiliacs on office space.

260. I recall at one point I got a big car bill, which was going to be a struggle for me to pay. I wondered if I could call the Macfarlane trust, but I didn't want to give Jan Harvey the satisfaction of saying no, so I ended up asking my parents because of how difficult Jan Harvey had made things.

261. When you got grants under Martin Harvey, you wouldn't have to pay them back. However, people did have to repay grants once Jan Harvey was in charge.

Section 8. Other Issues

262. I have received 2 ex gratia payments from the Government. The first of these was a payment of £20,000 in the late 1980s. The second was a payment of £25,000 in the early 1990s, which I received as a result of the 1991 litigation.

263. My parents and I don't recall signing a waiver for any of the sums which were received from the government.

264. My hope is that the Public Inquiry establishes what went wrong with the Infected Blood scandal, so that it never happens again. If there are people

that should be held accountable, then I would like to see that happen. If these things can be achieved, it would help me to put some of my demons to bed. I also promised my friend Paul GRO-B on his death bed that I would keep campaigning for the truth.

265. **I confirm that I wish to apply for anonymity.** I also confirm that I would be willing to give oral evidence to the Inquiry.

Statement of Truth

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

Signed... GRO-B ....

Dated........22/11/2018..............................

CHRONOLOGY OF MEDICAL RECORDS

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement).

Treatment record

09.10.68	Blood transfusion commenced
06.02.70	Blood transfusion – 1 pint suggested and 2 units cryoprecipitate ie Factor VIII in 2 pints of fresh blood.
17/18.02.70	Factor VIII
17.01.79	Factor VIII
31.01.80	Factor VIII
21.04.80	Factor VIII, 285 units, 245 units x 2
01/02/03.01.81	Factor VIII 650 units
06.01.81	Factor VIII 650 units
Undated but circa 81	Factor VIII 710 units
06.03.81	Factor VIII
07.03.81	About 4 units Factor VIII injected. No adverse reaction noted.
? April 1981	Factor VIII 800 units
Undated but on page Before 12.05.81	Factor VIII 800 units
21.07.81	Factor VIII 470 units
22.07.81	Factor VIII 470 units
24.07.81	Factor VIII 530 units
25.07.81	Factor VIII 450 units x 2
26.07.81	Factor VIII 450 units
03.08.81	Factor VIII 520 units
04.08.81	Factor VIII 470 units

ANONYMOUS

06.08.81	Factor VIII 470 units
16.08.81	Factor VIII 800 units
07.09.81	Factor VIII 535 units x 2
03.02.82	Factor VIII 520 units followed by Tetanus toxoid absorbed vaccine
18.03.82	Factor VIII 520 units
Early April 1982	Factor VIII on 2 days
22.07.82	Factor VIII 500 or 800 units (hard to read)
30.07.82	Factor VIII 500 units
15.09.82	Factor VIII 500 units
06.10.82	Factor VIII 240 units x 3
07.10.82	Factor VIII 560 units x2
Undated	Factor VIII 520 units
19.07.?	Factor VIII 500 units
20.07.?	Factor VIII 500 units
21.07.?	Factor VIII 500 units
05.11.82	Factor VIII 240 units x 3
06.11.82	Factor VIII 240 units x 3
11.11.82	Factor VIII 520 units x 1, 240 units x 1
16.11.82	Factor VIII 240 units x 3
19.11.82	Factor VIII 240 units x 3
16.12.83	Factor VIII 940 units + 720 units
17.12.82	Factor VIII 2395 units
18.12.82	Factor VIII 960 units
19.12.82	Factor VIII 1040 units

ANONYMOUS

06.12.83	Factor VIII
09.03.83	Factor VIII 1000 units
04.05.83	Factor VIII 560 units x 2
09.10.83	Factor VIII (Armour) 265 units x 3
18.10.83	Factor VIII 810 units
?.11.83	Factor VIII 500 units
04.01.84	Factor VIII 265 units x 2
27.04.84	Factor VIII (Armour) 800 units X20401
04.05.84	Factor VIII 780 units – pool of X33904 and X20401 Armour
14.05.84	Factor VIII 780 units pool of X33904 and X20401
30.10.84	Factor VIII 690 units
31.10.84	Factor VIII 690 units
01.11.84	Factor VIII 690 units. Blood unit number Y67602 x 3
06.11.84	Factor VIII 735 units Blood unit no: HLB3149
07.11.84	Factor VIII 705 units
02.12.84	Factor VIII 750 units
03.12.84	Factor VIII 660 units
20.01.85	Factor VIII 795 units
30.01.85	Factor VIII 265 units x 3 Batch: HL3213
22.03.85	Factor VIII 765 units
31.01.85	Factor VIII 765 units
05.03.85	Factor VIII 765 units Batch: HL3225
06.03.85	Factor VIII 765 units Batch: HL3225
21.03.85	Factor VIII 765 units Batch: 8CRV2210

ANONYMOUS

10.09.85	Factor VIII 1000 units
11.09.85	Factor VIII 800 units
17.09.85	Factor VIII 1000 units
18.09.85	Factor VIII 1000 units
19.09.85	Factor VIII 1000 units
20.09.85	Factor VIII 750 units
30.01.86	Factor VIII 1520 units + 1570 units
03.06.86	Factor VIII 755 units
04.06.86	Factor VIII 760 units
29.07.86	Factor VIII 1500 units
30.07.86	Factor VIII 760 units
20.11.86	Factor VIII 780 units
21.11.86	Factor VIII 520 units
08 (?).08.88	Factor VIII 750 units + 750 units
July 91	Factor VIII 10,000 units NHS for home use.
14.11.91	Blood transfusion – Clinical condition demanding blood transfusion "HIV +ve haemophiliac for suspected (?) Hep C +ve".
14.11.91	Factor VIII 2000 units x 2
15.11.91	Factor VIII 500 units daily for 7/7.
16.01.92	Blood transfusion.
21.01.92	Factor VIII
January 92	Factor VIII 2500 units Mono P.
January 92	Factor VIII 7500 units Mono P , home use.
January 92	Factor VIII 2450 units Mono P. (x2?)
January 92	Factor VIII 2450 units Mono P. Batch No's: IL39FP x 5 = 2450.

ANONYMOUS

January 92	Factor VIII 2,500 Mono C.
January 92	Factor VIII 2450 units Mono P.
January 92	Factor VIII 2450 units Mono P.
January 92	Factor VIII 2750 units Mono P.
January 92	Factor VIII 1960 Mono P.
January 92	Factor VIII 3270 units.
January 92	Factor VIII 2850 units.
January 92	Factor VIII 6000 units MON (Monoclate P?)
March 92	Factor VIII 2000 units Mono P for home use.
August 92	Factor VIII 3920 units Mono P.
10.09.92	Factor VIII 30,210 Mono P home.
24.08.92	Factor VIII 2000 units daily.
August 92	Factor VIII 14,000 units Mono P home use.
August 92	Factor VIII 18,900 units Mono P home use.
August 92	Factor VIII 3,080 units Mono P. Batch No's: J49701 x 11 = 3080
August 92	Factor VIII 2980 units Mono P. (x2?)
October 92	Factor VIII 30,800 units Mono P home use.
November 92	Factor VIII 29,925 Mono P home use.
December 92	Factor VIII 19,620 Mono P for home use.
December 92	Factor VIII 22,345 units Mono P for home use.
January 93	Factor VIII 15,600 units Mono P for home use.
15.04.93	Factor VIII 5000 units+ 7000 units (porcine) x 2
16.04.93	Factor VIII (porcine) 3000 units 12 hourly
17.04.93	Continue Factor VIII

22.05.93	Factor VIII 5000 units
27.08.93	Factor VIII
February 93	Factor VIII 17,790 units Monoclate P
28.02.93	Factor VIII
March 93	Factor VIII 5820 units, Mono.
March 93	Factor VIII 8245 units Mono P.
March 93	Factor VIII 1940 units Mono P.
March 93	Factor VIII 6305 units Mono P. Batch no's: J55507 x 13 = 6305. Red sticker stating "inhibitor screen positive 22.03.93".
March 93	Factor VIII 4160 units Mono P (x2?)
March 93	Factor VIII 3880 units Mono P.
March 93	Factor VIII 12,480 units Mono P for home.
April 93	Factor VIII 9700 units
May 93	Factor VIII (porcine) 4850 units, Hyate C
July 93	Factor VIII 500 units (Monoclate P)
January 94	Factor VIII NHS 20,000 home treatment
January 94	Factor VIII NHS 1060 units
16.03.94	Factor VIII 10,000 units
March 94	Factor VIII (NHS) 19,600 units issued for home use. Not on haemophilia database record.
March 94	Factor VIII 4900 units x 4 (unclear?)
March 94	Factor VIII 5000 units
March 94	Factor VIII 9840 units
March 94	Factor VIII 2450 units
March 94	Factor VIII 9800 units (x2?)
June 94	Factor VIII 23,200 units for home use.

June 94	Factor VIII 5,800 units for home use.

Virology results

14.08.91	Evidence of recent viral infection with Hepatitis A virus.
22.07.92	Hepatitis C virus antibody positive.
06.01.93	Evidence of past infection with Hepatitis A virus.

Significant entries

31.12.80 – 03.01.81	Pain in groin, Factor VIII for 3 days. Acute anaphylactic reaction – becoming faintly cyanosed, hypertensive "first time that he has shown any signs of reaction to Factor VIII. On discussion with the Pathology department it was thought that this may have been a reaction to some impurities in the make up of the solution as this had come from Leeds and future solution will be made up in a more purified form". H Ward, SHO Paediatrics, Huddersfield Royal Infirmary.
25.01.84	Thrombocytopenia, says developed probably following a viral infection.
21.03.85	Mother informed of HIV antibody and Hep B.
05.08.91	"I have carried out baseline investigations. His liver function tests are in keeping with probable chronic Hepatitis C. I am awaiting the HCV result, but his Hepatitis B surface antigen is negative"
19.08.91	"Just to let you know that this gentleman is positive for HAV specific antibody, which indicates a recent infection with Hepatitis A. I'm not sure how he caught this." Letter to GP from Dr Parapia.
12.09.91	"He may have caught Hepatitis A in Spain, but he has not suffered any undue complications". Letter to GP from Dr Parapia, Consultant Haematologist.
August 92	Coagulation screen – inhibitor screening, weak positive.

28.01.93	"Inhibitor screen showed a week +. Result in keeping with previous tests.
15.04.93	Talk of porcine factor VIII in handwritten notes.
16.06.94	"Mother very annoyed. GRO-B was seen alone and told 90% chance of dying in 10 years. Has Hepatitis C, with no explanation of the significance. Counselled re HIV and likely progression and Hepatitis C. Much less angry when finished." Handwritten entry by ? Bradford Royal Infirmary.
18.04.96	"He is aware of his Hepatitis C infection, he was informed of the diagnosis many years ago and his liver functions have been stable." Letter to GP, Dr Mason from Dr Parapia, Consultant Haematologist.
11.08.97	"I was aware of the implication of HIV (being exacerbated by Interferon), but was not aware it was as cast iron as it appears to be" Letter to Dr Parapia, Consultant Haematologist Dr Findley, Consultant Physician – upon reviewing the paper from the Lancet provided by GRO-B
14.10.03	GRO-B clearly needs to start treatment. I will obviously prescribe his anti-viral medication." Letter to GP Dr Mason from Dr McWhinney, Consultant in Infectious Diseases and acute medicine.
14.04.04	Letter to GP Dr Mason from Dr Stanley, Consultant Physician, Talk of GRO-B HIV infection becoming more advanced.
Undated	Letter to GP from Dr Parapia, Consultant Haematologist GRO-B received Factor VIII which has been implicated as possibly being contaminated with CJD. Had an obligation to inform GRO-B it is unfortunately another worry for him.
04.02.05	Letter 04.02.05 Dr Moreea, Consultant Gastroenterologist says he was diagnosed with non A non Hepatitis in 1981. He was subsequently found to have HCV Genotype 1.