Witness Name: Mark Ward
Statement No:WITN1591001
Exhibits: 0
Dated: January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MARK WARD

I, Mark Ward, will say as follows:-

Section 1. Introduction

1. My name is Mark Ward, DOB GRO-C 1969 and I live at GRO-C GRO-C with my civil partner, Richard Dudley-Smith.

2. Richard, has also provided a witness statement to the Inquiry; **WITN1199001**

3. 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

4. I was diagnosed with severe Haemophilia A at Great Ormond Street Hospital (GOSH) when I was a child.

5. My local hospital, the Lister Hospital in Hitchin, had previously misdiagnosed me with Christmas disease and then Von Willebrand's disease. I was treated at GOSH between 1972 and 1983.

6. GRO-B

GRO-B

7. I spent more time in the hospital or in the back of an ambulance than I did at home. When I was in hospital I looked in medical books and other literature my grandparents brought me. I liked to read throughout my time there; I wanted to learn. School wasn't really for me as I felt I did not fit in but I loved being creative, along with reading, aeroplanes and going to museums, as I was unable to do the things "normal" boys did like riding bikes and climbing trees.

8. I suffered from nosebleeds and I almost bled to death on a number of occasions; there were some really dark times. On one occasion I lost half of my life blood. As I lay in the back of the ambulance bleeding to death, I will never forget looking at my mother covered in my blood, her eyes showed the terror as I slowly slipped in and out of consciousness. The next thing I remember was people rushing everywhere my body being pulled around as I grew colder. My next memory is waking up at night being tied to the hospital bed. My arms attached to splints, with huge needles jabbing into me every time I moved, connected to a mechanical device called "the clock". The syringe sat in the top of the clockwork machine which would automatically administer the cryoprecipitate. Following bleeding episodes the haemophilia department would refer me to ENT who would then go through the process of cauterisation. Firstly, this involved snake venom soaked cotton wool being pushed up my nose, then cauterised. Later, this changed to cocaine as the

snake venom was deemed too dangerous. On occasion I was also given whole blood transfusions.

9. Staying in GOSH as an inpatient, I often woke up to find another child had died in the night. One night when I was in the hospital there was a baby crying. It was an indescribable cry. I knew something was wrong but I didn't know what. The nurse came in and I told her that the baby had been crying for a long time. I asked if I could give the baby a cuddle to help it stop crying, and she reluctantly said I could hold him for 5 minutes. He started to settle and after a sometime had passed she remembered she had left the baby with me, and came to take him back to bed. When she picked him up she realised that the baby was dead. The baby had died in my arms. I was told by the nurse that the baby had gone to heaven but he died in the arms of someone who cared about him. Death has just always been there in my life.

10. My mum and dad refused to send me to a specialist school. GOSH wanted them to send me to Lord Mayor Treloars. We lived right next to our local school and mum wanted me to stay nearby. Hertfordshire Country Council allowed me to attend my local school but imposed some rules on me doing so. My mum had to stay at home whilst I was at school in case I had to be rushed to hospital and I had to have a welfare assistant with me in the classroom and playground.

11. They had an assembly before I joined the school where all of the children were told they couldn't push or hit me because I bleed. This, coupled with the fact I had to spend my playtimes walking around the playground holding the welfare assistant's hand, instantly made me appear different.

12. As I went through junior school it was like Groundhog Day. I would be sitting in class when my nose would start to bleed; I was then rushed to London where I would stay for a couple of days before going back and starting the cycle all over again. It was a never-ending.

13. When I was 7 years old I fell over in the icy playground I fell awkwardly as the playground assistant was holding my hand. My left knee smashed into the ground. This was the beginning of many bleeding episodes and years of pain. As my knee weakened so the bleeds became worse and more frequent. This required more and more time off my feet. I spent long periods of time in hospital after this, sometimes with my whole leg in plaster.

14. My elbow had also became a target joint from being refused treatment as a baby through the misdiagnosis. Whenever I went to GOSH with a bleed they tried all manner of different things on my arm to improve it. They would trial all different methods and equipment, treating me as a guinea pig. This self-fused aged 11 which led to name calling and nasty comments. Kids would imitate John Inman, saying "I'm free" or call me poof and various other terms. I had blood taken a lot of the time.

15. When I was 12 years old I was taken to school in a giant baby buggy, which made me even more of a freak at school. My knee was swollen to a giant size. I knew deep down this was the end for my knee, and when I was on crutches pupils held doors open for me and then slammed them when I was half way through. People kicked away my crutches. I wasn't allowed to play sport so instead I was made to walk around the edge of the playing field watching on. When it came to the boys taking woodwork and metalwork classes this was deemed too dangerous for me, so I was put with the girls to do cookery and needlework; a haemophiliac, working with needles and knives!

16. In 1983, my knee would no longer properly straighten and it was decided by GOSH that I needed a knee operation. I was told if I didn't have an operation now I would be in a wheelchair by the time I was 21. My care was transferred to the Royal Free and the operation was set and about 3 months before I had the operation I was in a really bad way. My knee kept giving out and it was so swollen and full of built up congealed blood I couldn't even straighten my leg. It is in my medical notes from this time, the surgeon Mr GRO-D wrote that I am a 'polite young man, I believe with homosexual tendencies'.

17. I was in hospital for 6 weeks for the surgery, giving them access to any and every part of me they wanted. For the first week I was treated with Scottish NHS Factor VIII. This was the only time in my life I had been given Scottish NHS Factor VIII. On the day that I was discharged my parents and brother came to collect me. We went from the ward and into the Haemophilia Centre before leaving as my dad's car was parked in the haemophilia bay outside the door. Just before we left, Sister Patricia Lilly popped her head through the hatch that led to the treatment room and shouted to my parents: "Mr and Mrs Ward, do you want to know the GRO-B HIV results? They're GRO-B positive. See you next time"

18. We were stunned because we didn't fully know what that meant. We had no idea I had even been tested for anything, let alone HIV.

19. I hated them for the way we were told. They had had me in hospital for 6 weeks and were obviously testing me. They had every opportunity to warn my parents that HIV was a possibility but they didn't.

20. About a week later I went for an appointment with Dr Peter Kernoff with my parents for a follow up on my surgery and we were given some more information. We were told not to tell anyone about the infection because they couldn't guarantee our safety and if I was lucky I might live another 3-5 years. My parents were advised if we had things to do, then make them soon, such as if they wanted to take me to Disneyland we should go. I was told in another appointment slightly later that I probably wouldn't live long enough to leave school but definitely wouldn't have an 18th birthday party.

21. My mum was called to the school as the media insisted on connecting homosexuals, haemophiliacs, drug addicts and AIDS. She had to tell them that I was infected with HIV. The headmaster said he would have to monitor the situation and wanted updates from my mum. The bullying, name calling and intimidation intensified. I didn't just have a crippled arm that made me look gay but I would be asked over and over if I had AIDS yet. Many days during the final year I dreaded going to school not knowing what I was going

to face whilst being terrified I might even die there. I left the school in 1985 GRO-B GRO-B GRO-B

22. When I hit 16 years old, my hospital appointments got increasingly intrusive. They wanted to know everything about me and the questions about sex started. An all-female panel consisting of GRO-D Christine Lee and Eleanor Goldman asked me if I masturbated, if I used condoms, was I sexually active, did I have a partner, etc.

23. Over the years my sexuality (or speculation about it) is repeatedly mentioned in my medical records. I find this unnecessary and offensive. It also shows how comfortable medical professionals were/are to put their personal beliefs and contempt before their patient's welfare.

24. I was never spoken to as a person, because that isn't how they did things. Instead of seeing a frightened young man, I was met with hostility with a strict abrupt style of nursing. You couldn't question the doctors. We used to joke that the Royal Free wasn't a haemophilia centre, it was a coven of witches. If you dared to ask a question then you were made to feel very small and frequently told you were stupid and other cutting remarks.

25. I find it both amazing and impossible that there are no references to Hepatitis viruses in my medical records from either GOSH or the Royal Free. This was a period of time when the risks of Hepatitis viruses were being well researched and documented; some years before (in or about 1972) several young boy's data was used in a medical research paper at Sheffield Children's Hospital after being infected with Hepatitis and dying of cirrhosis of the liver. It is therefore impossible to believe that I wasn't tested for Hepatitis during this time. Following the transfer from GOSH to the Royal Free, both cutting edge research/medical schools no mention of testing for Non A- Non B Hepatitis is discussed or officially undertaken. This has always caused me a great deal of concern and made me question "how and why?" When I was at GOSH my notes were as thick as a telephone book, however when I

requested my records for the Inquiry my records are very scarce, which makes me believe that my notes have been purged of any references to Hepatitis and/or other contaminants. I am certain documents have been removed from my records.

26. Nobody ever warned my mother about the possible risks of infection to her. With a really bad nosebleed mum would be drenched in my blood. If I was in bed, the bath, etc she came into contact with my blood whilst helping me to clean it up. We did not realise that I was a risk to her and no one warned her that I was. This was not only reckless but they were playing with my parents' lives as much as they were with mine and it is a miracle that she was never infected.

27. I am certain that my sexuality has played a huge part in compromising my treatment and me frequently being treated differently to heterosexual haemophiliacs. My mum has admitted they would never speak to GRO-B GRO-B another man the way they do to me. GRO-B GRO-B

28. In 1991 I attended a review with Professor Christine Lee. We were in her office and my notes were in the middle of us. I remember seeing her filling in a form which had separate boxes with different titles, one said HCV on it. I asked what this meant as I assumed it was a type of HIV, she replied 'oh no that's your Hepatitis C, but you don't need to worry about that because you'll be dead from AIDS long before that can affect your liver. When you were infected with HIV, you got Hepatitis C as well, if you get one you get the other". This was how I found out about my Hepatitis C infection, and I was given no real information about the infection other than this. I was led to believe that the Hepatitis C piggy backed in on the back of the HIV and therefore if you had HIV it was inevitable that you got Hepatitis C as well.

29. In my medical records there is a note dated 22 May 1991 which states I had not been tested for Hepatitis C. The way it is written suggests we had a cosy little chat about Hepatitis C and I then agreed to be tested, this is completely

untrue. I therefore believe I was officially informed of my infection in the second half of 1991.

Section 3. Other Infections.

30. I was told by a letter 2nd January 2001 that I was at risk to vCJD, having been treated with implicated batches of Factor VIII. I was later told the batches were made using the blood of someone who had died from the disease.

31. I have gathered information through requests and accessing my medical notes which confirm I have been infected with and exposed to many other pathogens through contaminated blood and blood products including (but not limited to) those contaminants listed in the Penrose Inquiry Final Report. The medical term used for a patient like me who has been infected with and exposed to so many pathogens is "super infected".

Section 4. Consent.

32. Neither my family nor I ever consented to being tested for any pathogens or contaminants including HIV or Hepatitis viruses; it was completely devastating to us when each time we were informed of my diagnosis.

33. I have always been seen as nothing more than a piece of meat and I have no doubt that I was used as a guinea pig for the Scottish treatment to see whether I became infectious.

Section 5. Impact

34. Due to loosing so much time at school I was constantly treated as if I were stupid. At GOSH I spoke to Royalty and Harley Street experts who hung on my every word. I regularly assisted medical students in their training as I "was a bright lad". I did have a supportive school doctor who organised an hour of home tutoring per week but once I reached secondary school I was made to feel like a dunce. I was placed in with the 5th year remedial class during the

winter months despite being younger than them. I had teachers telling me I wouldn't amount to much. I felt on a number of occasions as if I had been written off and that people were just going through the motions because there wasn't much point.

35. Compared to other children I had a relatively isolated childhood for obvious safety reasons and had to be protected from any potential threats.

36. I was asked by the careers advisor what I wanted to do. I said I wanted to work with aeroplanes. He told me to get my head out of the clouds, airlines wouldn't look at someone like me. I should think about something more suitable, like working in a shop. I passed all my exams I took and couldn't wait to leave my school days behind me. I finally left school in May 1985.

37. I applied for any vacancies among various different airlines' youth training schemes. Britannia Airlines accepted me and I was given a position, before I was later told that they had over-allocated places and there was no longer a position available for me. I thought at the time this may be a result of my haemophilia and maybe the careers advisor was right.

38. However, shortly after I was invited to Heathrow to take an entry test for the British Airways' Youth Training Scheme. After the test I was put straight into an interview. The YTS manager was concerned about the travelling from Hertfordshire to Heathrow, so I asked if Gatwick had a scheme as my Grandmother lived closer to there. My file was sent to Gatwick and after a second interview I was awarded a place on the scheme after they expanded the group intake from 12 to 13 places to make room for me.

39. The Government then extended the scheme for a further year and I was kept on by BA.

40. I absolutely loved working for BA as I loved aeroplanes so much. As my HR manager knew this, she arranged for us to fly to Toronto on a 'familiarisation flight' so that I could have my dream come true of working on a jumbo jet.

Working on the flight from Gatwick to Toronto, 5 days in Canada and then working the flight back to Heathrow to experience both charter and scheduled services British Airways/Airtours operated.

41. However, I was forced into living a double life, my dream airline life and my haemophilia life with its complications, as I wasn't able to tell people about my HIV; it was a secret that I had to keep to stay safe.

42. In February of 1987 I was asked to attend a surprise birthday party for one of my college friends. I felt so happy as to me this finally meant acceptance. A couple of days later I was asked by different friends if I would like to go to Belgium for the day. I declined but asked if they would take my brother as he was being bullied terribly at school. They agreed, as did my parents and on 6 March 1987 they all travelled to Zeebrugge. I went to my party but as it began to snow heavily I left and started the coach journey from Gatwick to Luton Airport where Mum and Dad met me. We went to the local pub and it was here where we were told the ship my brother was on had sunk. The Herald of Free Enterprise will stay with me forever. We spent 3 days not knowing if he was dead or alive. Eventually, through a contact at Gatwick, I was told his name was on the passenger list of a recuse flight. I will never forgive myself for putting him through that nightmare. I do believe my brother was lost on that day as the person who returned was never the same again, nor was our family.

43. In 1989 I was taken on permanently as a Senior Cargo Assistant at BA Cargo Gatwick.

44. Following the merger with British Caledonian Airways a large number of staff left the airport which created a lot of overtime. Then the impact on passenger numbers brought on by the first Gulf War meant many airlines faced major financial difficulties which saw some job losses. However, BA cargo at Gatwick utilised every opportunity and so managers really put pressure on everyone to do more shifts. I worked double shifts for weeks and whenever they needed someone to cover I always did it. I lived and breathed British

Airways. I absolutely loved every part of my job and being part of something so special. Despite being a severe haemophiliac I had the best sickness record in the place because I was so determined to work. To my knowledge, I was the first severe haemophiliac to work as front line staff for a major airline anywhere in the world.

45. Homophobia is a problem I have had to encounter my entire life, and this has been exacerbated by my illness.

46. When I asked as a teenager if there were many gay haemophiliacs, I was told there weren't any. I was made to believe that I had been infected with my homosexuality just like my other infections – that I had been given AIDS, the 'gay plague' so I hated myself. People were lead to believe it was "the gays" fault that we were infected with HIV because their blood had somehow got into the treatment, mostly in America.

47. I have encountered many people who believe the blood products had been infected by the 'gays', and as such I feel resentment from many people inside the infected blood community. I have been told people are unhappy with me doing so much media because people might think that all haemophiliacs are gay. I am excluded from meetings because other victims appear to have priority

48. I have had hepatologists advise me that I need to be more careful with my sexual practices because they assume I become infected as a result of my lifestyle because I am gay.

49. When I met another gay man with haemophilia who had been infected through contaminated blood products, he told me that he had been told the same things as me by the Royal Free (ie. that there weren't any gay haemophiliacs). I was later told by Christine Lee that any gay haemophiliacs had found god and had chosen to live a life of chastity. "They don't have sex".

50. Dr Thynn Thynn Yee at the Royal Free in particular was extremely rude to me. When my teeth started to shatter she told me that I should probably learn to brush my teeth better, and she also later told me when I had a rash on my back that I had acne and should learn to wash properly. After seeing a dermatologist, they realised it was a result of my medication and it was able to be remedied. I was outraged by her actions and accusations, especially as I had always taken such pride in my hygiene and how I looked, so for her to say that was very hurtful.

51. On another occasion I broke out in facial warts and Dr Yee wrote a referral letter, starting: 'this homosexual man with AIDS…'. There was no reference to the fact that I had been infected through contaminated blood products or was a haemophiliac.

52. I rented a house **GRO-C** through BA, where part of my rent was put towards buying the house. I knew I was going to die but I wanted to leave something for my mum and my Nan.

53. I then met a friend through work who introduced me to the gay scene and took me to my first gay pub. In those days it was still very much an underground scene but I knew straight away that it was me. We went clubbing and had fun. I felt I had found where I truly belonged; I was in a job I loved and at that point in my life it was like all my dreams had come true despite the HIV.

54. Then one night, when I was home alone, there was a knock on the door from a woman who was crying and said she had been attacked by her husband with a carving knife. She was an American woman named Alex. I calmed her down and we talked. I agreed that she could stay the night in my spare room as she didn't want to go back to her husband because she was scared.

55. A friendship slowly grew and she gradually became more involved in my life. At that time my relationship with my father had deteriorated and Alex was the person who apparently understood me. My friends were really concerned and they tried to warn me about her but I didn't listen. I couldn't see the woods for

the trees. At that point I still believed I was a lucky survivor and trusted people.

56. One day when I went to work I was called by my check-in supervisor who told me that the police were waiting for me. Alex had called BA and said that one of their employees who had AIDS had attacked her with a knife. Not only was this completely untrue, but it meant that my employer now knew about my infection. They contacted the Royal Free who were somehow (despite patient confidentiality) happy to confirm my diagnosis to my employer, and added that I suffered from full blown AIDS.

57. I was made homeless and had to watch Alex and her husband throw my possessions out of my bedroom window. I spent the next few months being harassed by Alex and her husband who tried to blackmail me into giving them my car. Eventually, I received a letter telling me that the CPS had dropped the charges due to lack of evidence but the damage had already been done; BA knew about my infection and my health was on the decline.

58. Just before Christmas in 1994 I was in a club when a man approached me and asked what my name was. We started to see each other and I had never been treated so kindly. On Christmas Eve he turned up at the flat I was sharing to say goodbye to me as he couldn't take the relationship further with me as he couldn't be with someone who was going to die and leave him. I decided then that I couldn't cope with anyone else ever walking out on me because of my health and I would be better off alone. My friends meant the world to me.

59. In November 1995 I suddenly fell very ill and was rushed to hospital. I was told that I had Cytomegalovirus (CMV). This caused me to get ulcers in my eyes, lungs and stomach. My CD4 count went down to 0.002. I thought I was going to die. Christine Lee came to my bedside and when I asked how I got this virus, she told me that it was my lifestyle; because I was gay.

60. She said I would be treated with an intravenous medication and I would have to stay in the hospital, but there was a strong chance I would die. My dad said I wasn't dying in hospital and would be coming home, where my mum could give me the treatment. I sat under a chandelier which had my drip attached to it at my parents' home.

61. At around the same time Christine Lee had a research paper published which highlighted the dangers still in the Factor VIII products which included CMV.

62. Whilst being treated at home, I gradually started to improve and my weight, which had dropped to just 4 and a half stone, started to increase. I was eventually able to recover and go back to Gatwick on reduced hours.

63. Years later I found out that from 1993 to 1995 they had been secretly testing me for CMV, which is why they were so quick to diagnose it.

64. I went to my parents' home and told them I wasn't feeling well, my breathing became more laboured and within hours it was clear I had a chest infection. Mum called the GP and a locum eventually came out. As she was shown into my bedroom mum explained I had severe haemophilia and was HIV+, the doctor stopped, took 3 paces backwards and told my mum to just call an ambulance as she rushed out of the door.

65. Around this time I was put onto a combination of medication which included Septrin, Clarithromycin and AZT by the Royal Free. The effects were frightening. My energy levels plummeted, I suffered a lack of concentration and I struggled to eat as I no appetite along with severe diarrhoea.

66. Because my appearance is so important to me, I was truly horrified when my teeth started to suddenly crumble and shatter, leaving the nerves exposed. Gradually, my smile started to disappear. I was later told that I needed 8 teeth out and it would be done under a local anaesthetic. The haemophilia department decided it was easier and cheaper to just take out all of my teeth. Over the course of two operations, I had all of my back teeth removed and then the rest of them.

67. Whilst admitted for the second operation the haemophilia team asked if I would consider doing a trial of Helix VIII – they had the license for a single infusion but not for numerous uses and the ability to be used for surgery. I agreed straight away as it would help kids who needed surgery. At the end of the 1 week trial I was taken off the safe synthetic Helixate and placed back onto the known dangerous Factor VIII blood products. I was given no reason why, seeing as the Helixate had worked so well for me. On each occasion I was given vCJD implicated batches of Factor VIII blood products. I truly believe this was attempted murder/manslaughter as they knew they were putting my life at risk.

68. They ripped my smile out and then left me with nothing. Months later I was provided with a set of dentures that never fitted properly, something I am forced to live with to this day. I made a formal complaint about this but it was treated with contempt as always.

69. When I had been made homeless I started living with friends GRO-C GRO-C I started to drink and take drugs when we went out, and I became a party animal. I had come so close to death with the CMV so I just wanted to go and do everything whilst I still could.

70. I started working at G.A.Y where I worked on the door meeting and greeting the customers as well as being in charge of looking after celebrities. I met a lot of people in the LGBT community and gained a lot more information regarding the HIV treatments that were available. After talking to HIV charities such as Crusade, they were telling me that there was a sense of hope and optimism, which was a mentality, not shared by the Royal Free haemophilia centre who remained insistent we were going to die soon.

71. I stopped trusting medical professionals and I became somewhat rebellious. I would turn up to the hospital with LGBT magazines that outlined these new treatments, where I was told that I shouldn't read stuff like that. You could have stood in front of these doctors with 100% proof and they would have still

told you were wrong. I also know from people I spoke to that the Royal Free were telling me one thing and other patients another.

72. Around 1996 I became ill again. I was told that it was suspected MAI – basically bovine TB – and if I wasn't put on treatment immediately I was going to die before the results could come through.

73. Not long after finding out about my infection, BA decided they could no longer keep me at Gatwick. I was sent to Heathrow airport to work on 12 hour shifts but with the highly toxic medication and the long hours my health suffered. I returned to Gatwick but I knew I was on borrowed time, either I would die or lose my job, feeling like a bystander. Finally, I was called to the managers' office where I was given an ultimatum, take medical retirement or the next time I went sick I would have my contract terminated. I had no option than to accept. This happened just before Christmas in 1996, and I formally retired at the end of January 1997. For me at least it meant I remained part of BA - the very thing I had been living for.

74. In 1997 I was taken back to hospital when I had CMV again causing the vision in my right eye to fail and the pupil remain fully open. I was treated in hospital for 2 weeks where my hair started to fall out. Professor Lee came to my bed and told me my HIV medication Ethambutol had to be changed as "it was killing people". She explained the drug was causing crystals to form behind the eyes which in turn caused brain haemorrhages.

75. I was sent home with a new treatment, when my urine turned a bright red colour. This made me panic and think I was bleeding internally. It was not until I went back to the hospital that I was told this was a standard side effect. I was more angry than shocked, this was nothing new to me as the haemophilia centre at the Royal Free had always been notorious with telling the truth and providing relevant information.

76. Just before I was formally retired I started my first long term relationship with someone who worked for BA out of Birmingham. Up until then I hadn't

wanted to get close to anyone. The hospital made me feel dirty, infectious and extremely uncomfortable about any relationships; particularly about sex. I moved to Birmingham to be with my new partner and my care was transferred to the Queen Elizabeth Hospital (QEH), Birmingham.

77. Following my move to Birmingham I got a job as a barman in a gay nightclub but never really liked being on that side of the bar. After the second CMV reoccurrence I joined Thomson Holidays in their call centre. Whilst working there my relationship fell apart and become more violent. By October of 1998 I was on my own with my pets and the temporary contract with Thomson had ended. I spent a lot of time watching TV, curled up on the sofa.

78. I then got a job in Bourneville at a management training centre as a receptionist in 1998/9. I really liked it there and I threw myself into the job. The only problem was the manager, a woman GRO-D who was openly homophobic. I always felt she was jealous of the way I fitted straight in with the other staff and liked.

79. One weekend when I was working I was approached by a new supervisor who began to ask me how my haemophilia affected me. She told me that she had a friend in Australia who died after getting AIDs through blood products. Nobody had ever known about it and I was shocked at first that someone did know the truth and then I confided in her that the same thing had happened to me.

80. When I went back to work the following week, GRO-D started acting very hostile towards me and started making me do tasks that I had never had to do before and would struggle to do with my bad elbow. Whenever I told her I might struggle due to my fused elbow, she kept saying 'are you refusing to do it?'.

81. This continued for a few weeks when I received a call telling me that my Nan was unwell. GRO-D told me to take a few days holiday, and I went to the hospice where I could barely recognise my Nan as she had been consumed

by cancer. She passed away crying out for god to help her with me by her side. That's when my world literally fell apart. She was my best friend, my rock and she believed in me and everything I did she supported. Nan was the first person I that I had told about my sexuality.

82. I went to the GP the next day to get a sick note for not being at work, which I sent up to the office. We were given 2 weeks to clear her house and there was a slight delay in her funeral as the cemetery had a back log.

83. When I got back to work, everyone was acting very sheepish with me. I was told to go straight to GRO-D's office, where management and the owner were waiting for me. They tried to give me a disciplinary for breaking the rules of sickness, as apparently, I was meant to have called them every day to tell them how I was feeling. I was enraged. I asked if that meant me telling them every day my Nan was still dead but we got her a nice box to bury her in. I knew it wasn't because I had taken the time off with my Nan's death, I knew it was because they had found out that I had AIDs. I threw my resignation letter across the table as I refused to be treated like that. GRO-D had me escorted from the premises.

84. Shortly after all of this I went for a job at Birmingham airport as a passenger service agent and was immediately accepted. This started in Easter 2000. My career was on the up again. I was only on a part time so I could look after my dog and two cats but I would do lots of overtime. The hours were extremely unsociable but I made sure I got my rest. Some shifts would start at 03.00, including Christmas day but I was loving it.

85. I went to Gran Canaria with a group of friends where the last two days of my holiday I couldn't get out of bed. I didn't feel right. I managed to get out of bed on the last day and phone my mum and ask her to tell the hospital I would be going straight there from the airport on my return.

86. When I returned we went straight to the hospital where I collapsed. When I came back around, I was in an MRI machine. I couldn't feel my left arm. They

told me that I had a lesion on the right motor cortex of my brain that had caused an internal bleed. "You've had a stroke Mark".

87. The doctor informed me I had something called JC virus (he explained it was a brain virus similar to BSE) His advice was to go home, get my affairs in order as I had "weeks not months to live". I was told that I was going to die. The doctor couldn't tell me exactly how long I had to live, but as it affected me it would shut down my brain until I was a vegetable on life support. My care was then transferred to the Haemophilia Centre at the QE2 in Birmingham.

88. When I returned home from the hospital after telling me this, there was a letter waiting for me, informing me I had been exposed to vCJD.

89. I sold my car and made other preparations before my death.

90. It was shortly after this that Mark Simmons came into my life. Mark was a social worker connected to the haemophilia unit at the QEH and he was able to educate me in a way that the doctors had never been able to do before. He instilled my rebellious side and I started to fight a little bit more and question what the doctors were telling me.

91. On a visit to the QEH, Dr Wilde the haemophilia consultant discovered through test results my blood was highly toxic and my liver function was being impaired. He contacted Thynn Thynn Yee at the Royal Free who said it was probably just my HIV medication. Dr Wilde took action and stopped all medication so that I could be properly assessed.

92. This was a trait of the Royal Free that they kept adding more and more medication to my regime but never reduced any unless they absolutely had to.

93. I was placed onto a new regime which included clonazepam and started to feel slightly better, regaining a little bit more use of my left arm, however I started to suffer from involuntary hand movements (crabbing).

94. I went back to work and I was on check-in where I was serving some customers when I started to feel really ill. The customers started accusing me of being drunk, and the next thing I knew I woke up being stretchered out of the airport. Despite the fact I had collapsed due to my illness, my boss came into the hospital and fired me at my bedside whilst connected to machines.

95. In April 2003, when I was feeling better, I went on another holiday to Gran Canaria which is where I met my partner Richard. We met at a bar and there was an immediate connection. I took Richard outside and told him everything about my haemophilia and my infection, and I told him if he wanted to run for the hills, he wouldn't be the first. I had to tell him everything there and then because I knew he was someone special. Fortunately, Richard was not phased and we have been together ever since.

96. Following an MRI in 2003 I was told that the legion on my brain had disappeared and I was gradually taken off the various medications prescribed by my neurologist at the QEH.

97. In 2004 I moved in with Richard at his flat in Brighton, returning my care back to the Royal Free. On my first visit back, Thynn Thynn Yee said she was glad I wasn't dead and the whole brain episode could not be explained. My official diagnosis was (and remains) that I am "a man of mystery". She also felt the need to remind me that I was still going to die from AIDS or liver failure brought on by my Hepatitis C.

98. On one occasion I went to the Royal Free where Christine Lee wrote in my notes that I had 'no bladder issues at present'. I have been reassured that this was just a throwaway line and that they just write things like that, however I now suffer from bladder problems and they refuse to accept that my infections have anything to do with it. This seems extremely strange to me as why would they write that I wasn't suffering with bladder problems at present if they didn't think it would be a possibility in the future? To me it implies that they suspected it was going to happen, however they continue to deny this.

99. I have a problem when I urinate now. I asked Professor GRO-D if they can do renal tests and try to get to the bottom of it, but he just kept reassuring me that everything was okay and he wouldn't refer me to a urologist. Eventually he sent a referral to the urologist asking him to look at me as I am very persistent and could not be dissuaded. When we went into the room with the urologist I introduced him to Richard and he completely blanked him.

100. The urologist ran tests where I drank lots of water and went to urinate through a machine to record the flow rate. When I returned and he saw the reading, his face went pale and he rushed out of the room. He told me he believed I had a blockage and with my haemophilia he couldn't guarantee my kidney wouldn't rupture. This meant my life was in immediate danger. I was urgently referred to nuclear medicine for further tests. They displayed my kidneys up on a screen which showed the severe damage to both kidneys. I had a right atrophic kidney working at about 16% of normal function. My left kidney was operating at 24% and covered in odd shaped nodules. I was told I had first stage renal failure caused by the old HIV medications. I have checked back through my blood test results and, prior to this, I hadn't had a normal renal function test result since 1990.

101. I was given the option of a tablet which may help to relieve some of the flow problems. I was on this tablet for a month and the side effects of the medication sucked all the life out of me. I became more and more depressed; as the world became darker, so did my mood. Within days of taking the last tablet it was like somebody turned up the lights. I could feel myself getting back to normal again.

102. I was later offered an operation which would mean I would never be able to ejaculate again. The doctor who discussed this option with me said I could have the surgery 'if my wife and I are finished having children'. This was completely inappropriate and showed he had not bothered to consider any of my medical history before the consultation.

103. Dr Yee and Dr GRO-D were adamant that I should go on Interferon to cure my Hepatitis C. I said I would have to go home and speak to Richard first, to which Dr GRO-D said 'well if you don't want my help then get out'. Mark Simmons advised me to stay off Interferon as long as possible as psychologically and physically he didn't think I would survive; however this didn't stop Professor Dusheiko trying to push it on me.

104. In December 2005 I had a meeting with Dr Yee and Margaret Johnson where I was told that I had cirrhosis of the liver. We then discussed the change in my HIV medication to assist my liver which was at risk from toxicity. This was then confirmed in writing to my GP, stating "Mark's chronic hepatitis C, which has led to cirrhosis". I had an ultrasound which showed the bright scarring on my liver and it was recommended I be seen every 3 months to check on the damage to my liver. This never happened but I still had doctors trying to force Interferon on me.

105. In 2006, Professor Dusheiko wrote in my medical notes that I had a very hypoechoic liver and I was going to speak to my partner about going onto Interferon. Apparently, they had earlier tests that showed the virus had 'cleared', however they had never told me about this.

106. In 2007, during a consultation with a gastrologist for my worsening stomach problems, I was asked what treatment I had taken for my Hepatitis C. When I replied "none" the doctor said "Oh, I suppose it disappeared all by itself did it"? I asked what she meant and she said I had an undetectable Hepatitis C (HCV) viral load. I replied "No that's my HIV". So she had me retested for HCV. I was then informed that I did not have Hepatitis C any more. I had doctors trying to force Interferon on me when I had seemingly already cleared the virus! After that everyone refused to talk to me about Hepatitis C, and, to this day, no one has explained why/how I managed to clear the virus after being infected for so long.

107. When I said I was frightened that the Hepatitis C may be lying dormant and it could still be on my brain, I have recordings of Dr Dusheiko saying 'what do

you want me to do, drill a hole in your head?'. He also told me that Hepatitis C simply disappears 'all the time', in complete contradiction to what he had previously told me. It cannot suddenly disappear - your levels drop over a long period of time. This triggered a bad anxiety attack (also recorded) If this is what happened to me they must have been ignoring my viral load tests. I am aware of very few people who have cleared the virus naturally after having chronic infection for more than 3 decades.

108. I was told by the urologist after examination that I had an enlarged prostate with nodules on it, and due to my long term infection with HIV there was a possibility I may have prostate cancer. I was taken into hospital where I needed a general anaesthetic for an exploratory cystoscopy. The plan was that they would inflate my bladder with fluid which would enable them to take a better look.

109. I had already informed the haemophilia centre in writing about inaccurate medical information in my hospital notes. I informed the doctor who came to take my blood and put in the cannula that my medical information was incorrect. It said that I take 75mg of sleeping medication Zopiclone per night – so I had to correct him that it was actually 7.5mg per night. He was incredibly patronising, patted me on the hand as he tried to reassure me that they were the doctors and knew what they were doing, despite this being a mistake that could have killed me. When he left the room I had to amend my medical notes and put a decimal point there myself. I am terrified that I am going to die as a result of a doctor's incompetence or ignorance.

110. I was placed "nil by mouth" from midnight and kept in hospital for the whole day. They ran their routine tests and at 18.00 I was told that the procedure wouldn't be happening. I asked if this was due to my vCJD risk, to which I was told they couldn't possibly disclose that. I was told to go home and the procedure was rescheduled for a week later. The second procedure was that also cancelled without any explanation. Nothing happened after that despite me chasing them a number of times still suffering from the flow problems.

111. A year later I was sent an appointment to have a regular cystoscopy.

112. I contacted the Royal Free Haemophilia Centre regarding the appointment as it stated I might need antibiotic cover for the procedure. I asked if they would do this or my GP. I was reassured my GP would do it "if required".

113. When I walked into the room to have the procedure done the doctor told me he was going to give me an intramuscular injection of antibiotics. I told him I was a severe haemophiliac and couldn't receive those injections, so he said he wouldn't give me the antibiotics at all – despite the fact that a few seconds before he thought I needed them. So I asked for oral antibiotics which he refused to give me and he threatened to cancel the procedure. So I said if he wanted to waste all that time and money for the sake of a couple of antibiotics for a man with AIDS then fine. I also told him I would report him. He proceeded to perform the cystoscopy very roughly and I felt extremely violated. I went with my Mum straight to the haemophilia unit to warn them in case he wanted to give any other haemophilacs an intramuscular injection. But when I told Debra Pollard, one of the haemophilia sisters what had happened, she said "funny how you always find trouble, I think it's about time you went to a different hospital". The same threat I had said to me many times.

114. Months later I was prescribed a different medication by the urologist to assist with the flow. Luckily, as I trust nobody, I checked the paperwork and it clearly stated a person should not be prescribed this medication if taking HIV antiviral therapy. I contacted the Royal Free and never heard from the urologist again.

115. I received similarly unacceptable treatment when my ankle snapped in June 2008. **GRO-D** wouldn't even look at my foot and told me there was nothing wrong. They didn't fuse it until May 2009, and when I went for this surgery, the nurse was extremely rude to Richard and I; he was sucking his teeth every time he walked into the room. He simply refused to engage with us and finally I suggested I fill in my own hospital forms as I knew the important details and he didn't seem interested.

116. It was recommended that I stop taking my HIV medication a couple of days before the operation. The evening after the operation I started to feel unwell and so I waited until it was time for patient's observations to be done but the nurses refused to take my observations. This happened several times over the course of about 24 hours, despite me pleading for someone to at least just take my temperature. On one occasion the nurse put his face close to mine and said 'you're a very nice man Mark but you're an attention seeker, so lay there and shut up'.

117. I told him one final time that I really didn't feel well. I asked if he knew what was wrong with me, "I've got AIDS and had my medication was stopped days ago". He stormed out and spoke to the male staff nurse who told him there was nothing wrong with me, so I should shut my mouth. I really thought they were trying to kill me. I telephoned Richard in a full blown anxiety attack. He said he would come and get me but I was attached to several machines and if I unhooked myself I would bleed. Richard managed to get a HIV doctor to come and check on me, and the nurse lied to him and told him that he had taken my observations. After checking on me, the HIV doctor said I needed my HIV medication and he would get them for me ASAP. The nurse said "there, there feeling better now are we"? I replied "no, I haven't had my AIDS medication yet".

118. There was also a sign saying 'at risk of vCJD' above my bed and at the nurses station, which not only broke data protection protocols but left me vulnerable to the abuse which followed by everyone including the tea lady.

119. I put in a formal complaint as I suspected one of the reasons for my terrible treatment was because of my sexuality, but I was told that the Royal Free doesn't have homophobia because it is in Hampstead! It reached the point at the Royal Free where I refused to go alone because I didn't feel safe and I was aware they were trying to provoke a reaction from me so they could transfer my care elsewhere. I even wrote the Chief Executive stating I feared for my safety and life.

120. Since the lesion on my brain I cannot sleep without a cocktail of drugs. If the GP is unable to give me my sleeping pills, I can't sleep for days and I end up being really ill, having hallucinations and sickness until I'm hospitalised. I have told the hospital all of this, but they just say that I am addicted to pills.

121. I struggle to tell new people about my infection. There is still such a big stigma around the disease. If someone says they have cancer they have people to help and support them, but if you have HIV then you brought it on yourself or you are a monster. As a result of the media campaign in the 1980's, the stigma surrounding the disease was atrocious; people were having their homes set on fire. The word AIDS was never said in my house. GRO-B it was only recently that my mother was able to say the word. I watched as wards of gay men waiting to die were shown nightly on the news.

122. I also have to face the stigma of having to claim benefits. I live for my holidays, but I must justify everything I spend and do to everybody. I can't put pictures of my holidays on Facebook because I know people will start asking how I can afford it. We don't drink, we don't smoke, so if I choose to eat beans on toast for a month so I can afford a nice holiday then that's my choice.

123. I have had to deal with constant abuse and constant discrimination. I have been stigmatised by Tainted Blood and the haemophilia community for decades. I am excluded and only used when it's convenient. Even when friends pass away I'm forgotten -, out of sight out of mind - still being seen as thick or prone to throwing queenie strops. It's difficult to support people who obviously see me as a disposable commodity that they are happy to ignore my concerns or fears. A clear example was just before the Penrose report was published. I had people saying I had gone off the rails because I tried to warn the community it was a whitewash. I was silenced and thrown off the Tainted Blood Committee.

124. The only reason I re-joined Tainted Blood was because some close friends asked me to because of my knowledge and kindness towards people, they include Ade Goodyear, Steve Dymond (now deceased) and his wife Su Gorman.

Section 6. Treatment/Care/Support,

125. On one occasion I was taken to the Royal Sussex County Hospital when I thought I had appendicitis. They told me that I had a blood clot (as a severe haemophiliac!) and 'luckily' they wouldn't have to operate to remove it; I could just go home, wear tight pants and have warm baths. After going up to the QEH, they correctly diagnosed it as a psoas muscle bleed. Some of the incompetent treatment I have received is truly terrifying.

126. In 2006, following the American judge's decision to block our legal challenge against the pharmaceutical companies I fell into a deep depression. I was in a bad way mentally. The Royal Free were not interested so I turned to Body Positive, an HIV charity in Brighton to see a counsellor, who I still see to this day.

127. I tried on many occasions to tell doctors at the Royal Free about the terrifying dreams, flashbacks and psychological experiences I was having. Each time it was turned round onto me, I was exaggerating, lying or my concerns were just ignored. Before my ankle surgery in 2009 I had a major panic attack whilst waiting in the pre-op assessment area (this used to be the dental department which was at the heart of my dreams and flashbacks). Instead of going to the haemophilia unit I went to the HIV unit and saw my consultant who referred me to see the mental health team. Both a psychiatrist and psychologist agreed, as a result of what has happened to me, that I was suffering from PTSD and Phobic Anxiety Disorder. These make it extremely difficult for me to talk about everything. Completing forms for the DWP, EIBSS, etc cause me major anxiety attacks and my PTSD takes me to dark places.

128. In 2014 I went to the Royal Free for a haemophilia review. Whilst seated in the waiting area a security guard came in and told the receptionist he had been asked to come done for 12.15, the time of my appointment. My Mum was with me and I said to her, "he's here for me". If he follows us when we get called through I'm turning round and leaving. Whilst we waited the security guard paced up and down glaring at us both until a man I had never seen before appeared and called my name. This was Professor Nathwani, the new centre director. As we walked in the room Debra Pollard was sat there grinning at us, despite the fact I had specifically requested for her not to be present at the meeting as I had an outstanding formal complaint against her.

129. Throughout the entire review process I was constantly being provoked, spoken to with contempt, threatened and the information I provided was argued against. The term passive aggressive doesn't really cover the intimidation we were subjected to. I was told "this is the way we do things here if you're not happy with that I will transfer you to another hospital, I understand Southampton is a good hospital."

130. I was then sent across the hall to have my blood taken and again it was Debra Pollard who came to take my blood. Ms Pollard is renowned for always being able to find a vein and is the go to person called to do the injections for new born babies when needed as she is so good. However, when she went to take my blood, Ms Pollard jabbed the needle straight into my hand, wiggled it round and then said 'oh sorry I missed the vein'. As soon as we could Mum and I ran out of the hospital. My hand swelled up by the time I got home I had a bad bleed and needed to give myself another injection.

131. I put in a complaint and was encouraged to go to the police. I reported the incident to the Royal Free, Haemophilia Society, Camden Safeguarding, the Nursing & Midwifery Council and the Metropolitan Police. The officer was very kind but told me he could only look at the assault and nothing leading up to or outside the incident. He took statements from me and my Mum but the Royal Free blocked the investigation for over a year. The case was dropped due to lack of evidence.

132. Camden wrote to me saying they could not do anything. The NMC wrote saying they would not investigate as I did not meet the criteria. I called and asked what the criteria was, as I believed bullying, intimidation, threatening behaviour, homophobic abuse and assault was something they would be keen to ensure never happened again. I was told, they didn't like my tone and would terminate the call. So I said I would pass the information to my solicitor, to which she replied "you do that". The Haemophilia Society would not get involved because Debra Pollard had been a Society Trustee for decades, reaching the post of Vice President. All the implicated people/parities had or have power/control over the information, support and care we receive.

133. I arranged another meeting with the head of safeguarding at the Royal Free, along with the head of PALS. I was told the security guard had been called because I had spoken to one of the PALS staff and I apparently said I had a gun and I was going to shoot them in the haemophilia department. I now had the proof they were all out to get me kicked out of the hospital and a real vendetta was in action against me. Once again I feared for my life.

134. I think in a way I was suffering from Stockholm Syndrome as I was just unable to leave the Royal Free, despite my years of terrible care because I knew so many people there and in a weird way felt comfortable with the hospital. I just had to keep protecting myself each time I visited.

135. I transferred my care to St Thomas Hospital, London in October of 2014 and am much happier now.

136. I attended a Haemophilia Alliance meeting at the Department of Health (DoH) where we had discussions about calling an ambulance when receiving emergency treatment. We were advised on the protocols to follow which will enable our local ambulance service to arrange this. I approached my GP asking that I have an ambulance that can take me to London for treatment at my haemophilia comprehensive care unit in an emergency. However, they wanted me to sign a disclaimer to absolve them of liability if something happened to me on the way to the hospital. I refused to agree to this.

Unfortunately, no profile was created at SECAMB for me and after living at the same address for 14 years nobody knew I even existed when my GP sadly had to call on them in May 2018. Admitted onto a Ward with a terrible reputation for being the most violent in the Royal Sussex County, Bristol Ward

137. In 2001/2 I helped to write a booklet called 'You Don't Have To Be Straight To Take Factor VIII'. It was the first Haemophilia Society publication of its kind in the world. Designed to offer advice and support to men with haemophilia who were questioning their sexuality or identify as gay, who were going through what I had gone through whilst thinking that I was alone. Christine Lee refused to allow the booklet in her hospital and the supporting medical professional document were destroyed.

138. In 2004 I flew to Bangkok to give a presentation at the World Federation of Haemophilia Congress about the booklet and the ambitions for the project. Raising awareness, recognition and calling for support for homosexuals with haemophilia/ a bleeding disorder.

139. In 2006 I was asked to join the committee of a new support group, Tainted Blood. I have been an integral part of the group for over a decade representing the community at many events, meetings and protests. I have also given evidence to a Parliamentary Select Committee on the subject of vCJD. After being expelled from the group and the Haemophilia Society dropping the Men's Project I created my own support group for LGBTQ+ haemophiliacs/bleeding disorders called Haemosexual.

Section 7. Financial Assistance

140. My focus was on my career at British Airways from 1985 onwards. I had involvement and knowledge of the HIV litigation but at that point I still believed what I was being told; that I was one of the lucky survivors of a dreadful accident. We were blackmailed into signing a waiver for the 1991 litigation as we were told that if we didn't sign it nobody would receive anything. I initially refused to sign it as I considered my life was worth more than £23,000,

however this resulted in my Dad falling out with me and my family told me to stop being so selfish. I knew there were people dying and if I didn't sign they wouldn't have received a penny when they were in desperate need of money. I therefore had no option other than to sign and always felt betrayed by the DoH.

141. I received the Skipton Stage One payment, but I was denied the Stage Two payment as I had suddenly cleared the Hepatitis C virus. This was despite the fact that I had already been told I had cirrhosis and Richard and I were talked to by a consultant about liver transplants and potential death.

142. All of the hardship I have gone through has just been made more difficult by the various Trusts and Funds that were set up to support and help us. The DWP have made my life unbearable at times and have triggered psychological crisis which does include steps to take my own life. I honestly live in fear of a brown envelope coming through the letter box from the DWP.

143. When Richard and I were making plans to live together as a couple Mark Simmons suggested I contact the Macfarlane Trust (MFT) and officially add Richard as my partner. He said this would get me £5 extra a month. The MFT refused to accept Richard as they did not recognise same sex couples. This was the start of many years of fighting discrimination and for equality. I gained a great deal of support and Richard was finally added to my file.

144. Whilst I was preparing to die from the JC virus I did not receive any benefits and my mum helped me on a number of occasions. Mark Simmons said we should apply for benefits because I had a right to them. I was awarded benefits but placed onto the wrong one. This became the start of a 7 year battle with the DWP. I was asked if I "really had AIDS or did I just have HIV"?

145. Finally, in 2011, my then newly elected MP took my case to the head of Jobcentre plus and following an investigation I was awarded the back payments of £20,000 plus £2,000 ex-gracia payments for all the distress caused.

146. Not too long after I was placed onto the correct benefit I was sent a tax bill which was followed by another application form to swap to ESA so the degrading process of jumping through hoops started all over again.

147. I constantly have to justify my illness and my poor health to receive anything and I am not believed in anything that I say. I was told that the application for SCM would just be a tick box exercise; however my initial application was refused and the information needed to pursue this is held at the Royal Free who I consider my abusers.

148. In 2018, I encountered more problems when I applied for a grant towards a mobility car. Every car I went to apply for was then taken off the list of cars I could choose from. The newly revised regulations put in place by EIBSS insist you apply to Motability Charity before EIBSS and only then EIBSS might consider a grant of up to £500. Fortunately, because I keep my cars immaculate the Mobility Scheme gives a good condition bonus of £500. This meant I was able to get the car I wanted and I was able to stop pursuing the EIBSS for help as this wasn't going to get me anywhere. Plus I refuse to beg for something I have always been entitled to.

149. The EIBSS make it incredibly difficult for you to get anything and send you off to numerous other organisations before you can even speak to them. They adopted everything from the MFT, tweaking things to make obtaining support more degrading. They have the same method of making things so difficult for people that in the end they just give up and don't even bother applying.

150. Before the MFT could fully be shut down they had to disperse the funds held to the beneficiaries and an application exercise was put in place. We were told that the requested funds were to provide some much needed support/home improvements for beneficiaries.

151. Following this lengthy process the MFT did not use all of the funds (I have been told only half was given out to beneficiaries). As they still have money left and they couldn't shut down with money remaining, the Trustees decided

to give our funds to the Terrence Higgins Trust (THT), who have never acknowledged us haemophiliacs in the first place. According to THT, haemophilacs were "accidently" infected. It is all extremely secretive and we were not made aware of how much was left in the MFT reserves.

152. When I was told I had weeks to live in the early 2000's I contacted the MFT and asked for Sky TV as if I didn't have long left I just wanted to watch Disney cartoons. This was refused as it was deemed a luxury item, so my Mum had to pay for it for me.

153. I faced a sensitive issue from the MFT over their letter sent to beneficiaries regarding the Honeywell Trust – a trust set up to support "widows" – as I argued that it did not include male partners and Richard would therefore be unable to claim support when I die. I raised my concerns that their wording only protected 'wives and girlfriends', although my worries were dismissed by Jan Barlow until I threatened to go to the police about this blatant discrimination. The law clearly did not bother the MFT. In all her time at the Trust she refused to speak to me and the issue of equality was treated as insignificant. No other official organisation or body would support me on this issue because they might be seen to be supportive of homosexuality. This compounded the discrimination I and others have had to suffer for decades.

154. I pay for my Haemosexual work, campaigning and trips to speak at haemophilia conferences myself; I don't receive contribution towards this.

Section 8. Other Issues

155. Having looked through my medical records, I believe they have been purged of incriminating documents as I refuse to believe there wasn't a single reference to Hepatitis in my notes before the early 1990s.

156. I want people arrested for what they have done to me and others. These people knew what they were doing and they deserve to be punished. Crimes have been committed including blackmail and abuse of vulnerable people.

157. The Inquiry needs to implement the necessary steps to ensure this can never happen again.

158. The Royal Free Haemophilia Centre is at the heart of this scandal and all of those who worked there should be fully investigated. Some of the main culprits in all of this are Christine Lee, GRO-D and Debra Pollard. Debra joined the Royal Free in 1991 and she is of the opinion that because she wasn't there when it started it is nothing to do with her. She is entirely without compassion. I have lost count of the amount of times she has suggested I should change hospitals and that I am a troublemaker. GRO-D GRO-D GRO-D

159. Prof Dusheiko needs to be investigated by the Inquiry. He is hell-bent on giving anyone and everyone Interferon and his answer to anything is to up the dose of it. If you don't get the results you expected first time, give them higher dosages for longer periods of time. GRO-D GRO-D His belief is we should not get financial recompense for what happened as they were doing their best to help us. He then even sat on the board of the Skipton Fund and decided which of the people GRO-D would be able to receive financial assistance. He is also a board member of EIBSS which made my application for SCM impossible. I consider this a clear conflict of interests.

160. This conflict of interest has been ignored despite making the CEO aware of the situation. He has also refused to meet with me as the scheme has been designed so that he doesn't have to meet the victims he has a duty of care for. This is typical of the British government as seen within the DWP and DoH and Social Care. There is a complete lack of compassion and empathy.

161. I believe the Inquiry needs to look further into the other known/unknown viruses/pathogens and contaminants that were in the blood and blood

products. The potential threats to the blood supply along with the risks to the people who may have been exposed, including family members.

162. Harvesting the blood from Rwanda, shipping it to the UK and injecting it into the veins of little boys posed a major public health scandal which has been brushed under the carpet. However, we haemophiliacs are unique as we were the only patient group in the UK to be infected with HCV Genotype 4, the Sub-Saharan strain of the virus.

163. I have a gained a great deal of knowledge, data and a lot of research that can all be put to good use. I am an original member of Tainted Blood and have since founded my own support group, Haemosexual. I do a lot of campaign work, regularly speak to MPs and speak at haemophiliac conferences.

164. Pursuant to paragraph 2.9 of the Notice of Determination in the Award made to my Solicitors preparation of this statement does not cover investigative work. I would like to give evidence on the matters set out at Paragraph 163 above and I am unable to do so in this statement.

<u>Anonymity, disclosure and redaction</u>

165. I do not want to apply for anonymity but would like information relating to my family redacted.

166. I would like to be called to give oral evidence at the Inquiry in relation to my personal circumstances, investigatory work and other work in my relation to the support groups I have founded and been part of.

Statement of Truth

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

Signed..GRO-C....................

Dated...23rd January 2019.........