

Witness Name: Lee Terence Stay
Statement No: WITN1541001
Exhibits: WITN1541002 - WITN1541012
Dated: September 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF LEE TERENCE STAY

I, Lee Terence Stay will say as follows:-

Section 1. Introduction

1. My name is Lee Terence Stay. My date of birth is GRO-C 1968 and I live at GRO-C Kent, GRO-C I am divorced; however, I am still in contact with my ex-wife Tracey. I do not have children; however, Tracey has 5 children of her own. I currently live with a lodger who helps out with the bills. I do not work due to ill health since I left my previous job in 2008.
2. I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006.
3. This witness statement has been prepared without the benefit of access to my full medical records. I have recently received my medical records from Lord Mayor Treloar College (Treloar's), Kings College London, my GP (including previously missing records from Portsmouth and Kent) and additional information from the United Kingdom Haemophilia Centre Doctors' Organisation (UKHCDO) but I have been advised by Hammersmith Hospital

that they do not hold any records for me. I am willing to make these records available to the Inquiry.

Section 2. How infected

4. I was born with severe Haemophilia A, with less than 1% clotting factor, however, my UKHCDO records state that I have mild Haemophilia with a 19% clotting factor. I was diagnosed when I was less than a year old, following a head injury caused when I fell from a baby-walker.
5. I believe that Haemophilia runs in my family. My parents had 3 children before me; 2 sons born in 1940's who both passed away at a very young age and a daughter born in 1953 who is still alive. My parents thought that both of the boys were Haemophiliacs.
6. I have been treated at various Haemophilia Centres including: - St George's Hospital, London; Ashford Hospital (which was not an actual Haemophilia Centre); Hammersmith Hospital from February 1975, Treloar's from September 1980 under Dr A Aronstam and Dr M Wassef (being supplied with product from Hammersmith then the Isle of Wight during the holidays); Portsmouth from September 1987 under the care of Dr P Green; and then the Haemophilia Centre at Kent & Canterbury Hospital from September 2003 under Dr Mark Winter. I also had one visit at Exeter Haemophilia Centre. I attach the UKHCDO record of my Registered Haemophilia Centres at WITN1541002, however, I was not aware that I was also attached to '*Dr Craske's research work – not a centre*' and this was a complete shock when I read this.
7. My late father, William Henry Stay, who passed away in 1989, kept a detailed record of treatments that I received, including many batch numbers, which is available for inspection by the Inquiry. I was initially treated with Cryoprecipitate (Cryo) in January 1970 at St George's Hospital in Tooting, and then my care was transferred to my local hospital in Ashford, Surrey which was a very small hospital. According to my father's records, I continued

to be treated at Ashford with Cryo until February 1975 when I was transferred to Hammersmith Hospital in London aged 6. I was there under Dr Mibashan.

8. It appears that my first dose of concentrated Factor VIII (Hymofil) was given to me in or around March 1975 and I was also given Kryobulin during 1975. In or around June 1975 I appear to have suffered from what appeared to be an allergic reaction to Cryo, per my father's records: '*shivering develop ¾ hours later allergy tab*', from which point I only received Factor VIII concentrate (Hemofil and Lister). I exhibit my Hammersmith records for 1975 (please note the comment on the top of page '*Rec'd 28/8/76 from D. Craske*') and my father's records of my batches for 1975 at WITN1541003.
9. My father was taught how to administer the Factor VIII concentrate and I commenced home treatment from March 1976. It appears that I was given a variety of both UK and American products whilst under the care of Hammersmith Hospital, including Hemofil, Cryobulin, Lister and from March 1978 Factorate.
10. My father always took me to my appointments until I went to Treloar's in September 1980, aged 11, for my secondary education as the local authority did not want the responsibility of me being injured if I went to the local comprehensive secondary school. Treloar's catered for children with physical disabilities, including Haemophilia. There were 4 Haemophiliacs in my year but I am the only survivor. Treloar's had their own doctors at the boarding school site (the 'upper school'), which was run by Dr A Aronstam. Whenever I had a bleed I was transferred to the Haemophilia Centre and a doctor who had a duty would then prescribe my treatment.
11. I was at the lower school between 1980 and 1983. They did not have doctors there, so whenever I reported a bleed, a van driver was called to transport me to the upper school site to see the doctor and receive treatment. There were clinics held twice a day at the upper school, where we would be reviewed until the bleeds recovered. We would also be called for routine reviews, for orthopaedic assessments and blood tests. These blood tests were taken quite frequently but it was rarely discussed what the tests were for.

12. It should be noted that my father documented every bleed I had from birth including the name of every doctor that treated me and in many cases the batch numbers. This was up until the point when I started going to Treloar's and afterward just during the holidays.
13. Whilst at Treloar's, I was taught how to mix and inject my own treatment. I remember a graph that we would use to calculate how much treatment we needed to make, so the doctor would decide what percentage of Factor VIII concentrate would be needed to treat the bleed and the graph would tell us how many units would be needed, based on our weight. The aim was to get as close to that number as possible, based on using whatever treatment was available.
14. The product brands were never mixed in a single dose, but different batches of the same brand could be used to obtain the correct number of units, so if 1,200 units were required, we could use 2 x 500 units from one batch, and 200 units of another batch. Knowing what I know now, this increased the risk of infection because different batches would have different donors.
15. I do not recall being ever made aware of the risks associated with being treated with blood products. Risks were never a consideration back in those days. I was trained to self-treat between 1982 and 1984 and I do not recall being advised as to any risks of the treatment. I am not sure whether my father was ever told about the risks.
16. Hammersmith Hospital continued to supply my home treatment when I was at home during the school holidays until 1984 when my parents decided to retire to the Isle of Wight. As there was no Haemophilia Centre on the Isle of Wight, I believe that my home treatment was then supplied by Southampton General Hospital, although I was never a patient there.
17. I was based at the upper school from 1984 to 1987, so no longer needed transport to get to the Haemophilia Centre, which by now had purpose-built offices and laboratory. I did my CSE's and 'O' levels in 1985, then went on to

study 'A' levels at a local Sixth Form College in Alton. I still lived at Treloar's and transport was provided to get me to and from the Sixth Form College.

18. I note from my father's records (during the holidays) that I first received heat treated product (Factorate) on 24 March 1985, however, I may have received it earlier at Treloar's.

19. As a result of being treated with contaminated blood products I was infected with HIV and Hepatitis C. I exhibit my UKHCDO treatment record along with my father's batch records for 1983 and batch details from my Treloar's records for 1983 (reference TREL0000267-65) at WITN1541004.

20. It is not clear when I first tested positive for HIV as there are conflicting dates in my medical records. My summer term assessment on 29 June 1983 has a note of '*AIDS on 10.3.83*', and there is an associated letter to Hammersmith Hospital of 30 June 1983 confirming AIDS related investigations were carried out (with no attachment). My lymph nodes were closely monitored from 18 October 1983 for any Lymphadenopathy, which I believe can be a sign of AIDS as the entry on 13 November 1985 records '*no stigmata of AIDS*'. There are also clinical notes recoding checks on my lymph nodes. The clinical record entry from 17 March 1985 Spring Term Assessment records '*Anti HTLVIII positive when ... tested on 12.1.84*' corresponds with the letter from Dr Wassef of 19 March 1985 which confirms that I was '*tested for Anti HTLV 3 for the first time on 12.1.1984 and was found to be positive*'. My UKHCDO record for Patient HIV data which shows that I was infected with HIV between 7 June 1983 (date last negative) and 6 September 1983 (date first positive) which are also the dates recorded on the AIDS Surveillance and HIV Death Clinical Report Form dated 26 September 1994, however, I am not sure why all these dates are not consistent. I exhibit all these documents at WITN1541005.

21. I found out about my HIV infection at Treloar's around Easter 1986. As the school holidays at Sixth Form College were shorter than the holiday periods at Treloar's, there were a few weeks in the school year when only the pupils who attended Sixth Form College were at Treloar's. It was during one of those

weeks that I was called to the Haemophilia Centre for a meeting (I was 17 at the time). I cannot remember much about that meeting at all; but I do remember Dr Aronstam and a nurse being there. They told me that I had tested positive for HIV.

22. I cannot remember exactly what advice I was specifically given at that time. I had seen all the AIDS adverts so I knew that it could be transmitted via blood contact or semen. I was told by Dr Aronstam that I had been infected with HIV some time in 1983. I was told that my life expectancy would be limited; I think I was told I would have less than 10 years. I was also told not to tell anybody else about it.

23. From what I remember, I just felt numb. My mother had died the year before and my father was still grieving for her, so I didn't really know who to turn to. There was another haemophiliac who also attended the Sixth Form College. He was also called that morning and was given the same news, so we discussed it together and remained close friends until around 2002. I decided that I was not going to let my HIV diagnosis get to me and I was determined to carry on with my life as normal as possible.

24. I cannot remember whether I told my father about my HIV status when I went back home for the Easter holidays in 1986 or he was told about it by Treloar's.

25. I do not believe that I was provided with enough information to help me to understand and manage my infection. I was not given anything to take away with me from the meeting.

26. I think that I definitely should have been provided with information about my infection a lot earlier as I was infected with HIV in 1983 when I was 14 years old and told in 1986 when I was 17 years old.

27. I think that being given such serious diagnosis in a meeting was the right approach, as I was there with knowledgeable adults. However, I do not think that I was provided with enough support afterwards. My attitude at the time was this was just another illness to add to the collection, but not to let it get to me and or allow it to rule my life.

28. I do not remember exactly when I found out that I had Hepatitis C; however, see that as early as March 1982 my blood test request forms had a 'HEPATITIS RISK' sticker on it. The first positive Hepatitis C test result is dated 29 January 1997 and my records state that I was told on 30 April 1997 in a Haemophilia review. I was re-tested in 2002 by the Genitourinary Medicine / Sexual Health Clinic (GUM department) in Portsmouth. The Haemophilia person in charge made a cursory comment, saying something along the lines of '*you know you have Hepatitis C*'; I was never informed about my infection officially. The medical staff never told me how I could have been infected with Hepatitis C. I exhibit these documents relating to Hepatitis C at WITN1541006.
29. Following the second Hepatitis C test in around 2002 they referred me to the Liver Unit at the Royal South Hants Hospital in Southampton under Dr W Rosenberg for further investigation of my liver. After a few visits I was told that my liver was badly damaged, and they could not offer me any treatment to repair it at that stage.
30. While looking through my medical notes, I realised that there was a note stating that I was informed about Hepatitis C at Canterbury and that this was done through a lookback exercise in 2004. This was not the case. I was tested for Hepatitis C by Mr Hirri at St Mary's Hospital, Portsmouth on 12 February 1997 and was told that I was positive on 30 April 1997.
31. To my knowledge I was vaccinated for Hepatitis B while I was at Treloar's, so I was protected from it.

Section 3. Other Infections

32. On 18 February 2009, I received a letter stating that I was at risk of variant Creutzfeldt Jakob disease (vCJD) which I exhibit at WITN1541007 along with a letter dated 4 January 2010 stating there is no record of me being counselled for my CJD risk. There is nothing else that I am aware of.

Section 4. Consent

33. I never really thought of the consent aspect. Back in those days I did not have to sign any consent forms, so I never really considered it.

34. I do believe that I was tested for research purposes, without mine or my parents' consent. Treloar's wrote to Hammersmith on 30 June 1983 advising that he had undertaken AIDS tests on me and would repeat these before the end of term, which I have previously exhibited within WITN1541005.

35. Since my father documented my bleeds, I have a record every bleed I had from birth, including the name of every doctor that treated me; his records show that I was treated at Hammersmith from 1975 (aged 6 years old) onwards. But there is no mention of Dr Craske anywhere in my father's book; especially in his records for 1976 which I exhibit at WITN1541008, which suggests that some kind of testing was being done on me without my knowledge. As this was during my first treatments of Factor VIII, this would classify me as a '*Previously Untreated Patient*' or '*PUP*' while I was at Hammersmith. We were never given any feedback on any of this.

36. I also note from my Treloar's records that my father agreed to me taking part in a trial at Treloar's, which unfortunately is undated, which I exhibit at WITN1541009.

Section 5. Impact of the Infection

37. I was given Azidothymidine (AZT) in 1993, which I now know from reading my medical records was because my CD4 count went below 200 as seen in the UKHCDO '*Survey of Patients with HIV Infection*' completed by Dr P Green on 24 October 1994 which I exhibit at WITN1541010.

38. I then suffered from Pneumocystis Pneumonia (PCP) in September 1994, when I was 25 years old and I had to have a lot of treatment. I recall receiving a different combination of drugs at the hospital. I managed to recover and

return to work. However, since I recovered I have had difficulty breathing. I often became breathless and it took a long time to recovery my lung capacity. I understand my CD4 count remained around 10 for the next 3 years.

39. In or around March 2003, it was announced that my employer, P&O Ferries, was going to centralise its operations in Dover and that most of the shore side staff in Portsmouth would be made redundant. I was one of only a very few people who were offered a promotion to move to Dover with relocation costs. I moved to Dover by September 2003 and transferred my care to the Haemophilia Centre in Canterbury, under Dr M Winter.

40. Dr Winter continued with my existing HIV treatment, but became concerned about the effects of Hepatitis C He referred me to King's College Hospital in London, for them to assess my liver. I went to see Dr Paolo Rizzi at the Institute of Liver Studies at King's in May 2005 and he sent me for blood tests. I remember getting a call before I even got home, telling me that I needed to come back as soon as possible.

41. When I returned, Dr Rizzi told me that my liver was severely compromised and that the only option would be a liver transplant. I went through numerous tests and after adjusting the HIV medications again to make them more compatible with the possible effects of the transplant, I was placed on the transplant list in November 2005.

42. At this stage, my work was very cooperative with the fact that I could get the call at any time that a compatible donor liver was available. Up to this point, I was in charge of a small team, but to avoid significant disruption by me suddenly not being there, they offered me a '*sideways*' move so that I could work independently on projects, whilst another line manager took over my team.

43. On 18 July 2007, I got the call and was rushed to King's. The transplant was a success, and the bonus was that the donor liver was able to produce its own Factor VIII, meaning that I was now cured of Haemophilia. It took a while for the hospital to get the drug levels right, because I needed one drug to

suppress my immune system to prevent my body rejecting the liver, while I still needed the other drugs to control the HIV, which caused them to interact with each other. They eventually got the levels right and I was allowed home. After several months of recovery, I started to return to work on a part-time basis.

44. After my liver transplant I had a drip in my left hand, which caused a few of my fingers to go numb. Nobody knew what the problem was. I had tests done at the Neurology Department at King's and I was found to be suffering peripheral neuropathy in my fingers and toes.

45. The current immune suppressant that I am taking, called Prograf (tacrolimus), interacts with my HIV drugs, which results in the need to take it a lot more sparingly than most people. It took the doctors a while to figure this out.

46. I also suffered from a Seminoma (testicular cancer) in October 1998. I am not sure whether there is any link between my HIV and Hepatitis C infections and this cancer, but I suspect that the speed with which it grew was affected. I recall that it went from nothing to being huge in only a couple of weeks. It was shocking.

47. Some side-effects of the drugs which I have been taking include upset stomach and bloating, and this came across a lot in the earlier treatments.

48. In November 2013, following a change of blood pressure tablets, I was complaining of a pain on my right side and blood tests showed that I was severely dehydrated, and my potassium level had gone through the roof. I was admitted to Queen Elizabeth, The Queen Mother Hospital in Margate. Initially, they thought the problem was due to an interaction between the new blood pressure tablets and the existing medications I was on but following a CT scan they discovered a mass on the psoas muscle. A biopsy was performed, and the mass was identified as Burkitt's lymphoma, which is a very aggressive form of non-Hodgkin's lymphoma, which if left untreated is fatal.

49. When I researched Burkitt's lymphoma, I discovered that people who have HIV or who have had an organ transplant have a much higher risk of developing it. The medications taken after the transplant suppress the immune system to prevent a patient's body from rejecting the liver. This is why I believe that I got the cancers, as my immune system was suppressed by HIV and the drugs after my transplant.

50. I was admitted to King's and was immediately started on intensive chemotherapy. I was made aware that the treatment would render me infertile, but it was essential that the treatment was commenced as soon as possible. I was initially given 2 cycles of chemotherapy, which had very unpleasant side-effects including ulcers in the mouth and throat, and hallucinations. I had to be kept in isolation the whole time because of the risk of me picking up infections whilst having and recovering from the effects of the chemotherapy. I was in hospital for a total of 3 months, and then allowed out for a couple of weeks before returning to start a further cycle of treatment which took just over another month.

51. The third cycle was even worse, so much so that they said after this cycle they wouldn't be able to give me anymore as my body wouldn't take it. I finally came out of hospital in June 2014, but when they reviewed the scans following the treatment, they said that the mass was still there. At this point I was given a DS1500 form, which indicates that I was not expected to survive another 6 months.

52. In order to get another opinion, I was sent to St Thomas' Hospital for more tests. St Thomas' felt that the mass had shrunk slightly and suggested that because I was not in any discomfort, the mass may no longer be cancerous.

53. The chemotherapy reduced my platelets to near enough zero, which could prevent my blood from clotting. Also, my haemoglobin levels kept dropping so over the next 18 months I had to attend hospital twice a week to have my blood levels monitored and had regular platelet transfusions and blood transfusions sometimes twice a week. Eventually, by 2016, they had returned to near normal levels.

54. Chemotherapy had a massive impact on me on a mental level. It caused me confusion, issues with memory, whereby I could not remember things, including my own date of birth. I also had a couple of epileptic seizures and a subdural haematoma which had to be drained. I have also realised that I am a lot less patient than I used to be.
55. Hepatitis C also had a massive impact on me physically. I do not believe that it had a massive effect on me mentally as I was always very determined, I never let it make me feel down and I just got on with it.
56. In terms of the physical effects of Hepatitis C it caused me an awful lot of tiredness. I had very little sickness up to that point and had a very good sickness record at work as I was determined to work regardless.
57. I was always aware that the donor liver would be re-infected with Hepatitis C and would start to deteriorate but I was conscious that King's were keeping an eye on this and hoped that newer treatments would come along before the liver was too badly affected, therefore avoiding the need to subject me to Interferon.
58. I needed to wait for my Hepatitis C treatment for around 12 to 18 months as my blood levels were very low after having chemotherapy for lymphoma. These new treatments were coming out as I was recovering from the chemotherapy, so they managed to get me on the Early Access Scheme. I was given Harvoni with a reduced dose of Ribavirin over 12 weeks in 2015 and managed to clear the HCV virus but I still require regular monitoring of my liver every 6 months after my transplant.
59. I still suffer from tiredness and I have irregular sleep patterns; sometimes I cannot fall asleep until around 3am and then I sleep until midday the following day, which I believe is a direct result of the Hepatitis C. I can manage it better now; however, it was a lot more difficult in the earlier years, and my job had to be adjusted to cater for that and I worked 12pm to 8pm or 9pm. It was fine until I was made redundant in 2008.

60. At the beginning of 2017, a lump appeared on my lip. This got bigger quite quickly and it was diagnosed as a Squamous Cell Carcinoma (SCC). Once again, SCC's are more prevalent in patients who have HIV and/or organ transplants. After several false starts, it was removed on 22 June 2017 at the Kent & Canterbury Hospital by Mr J Mackenzie, and skin from my cheek was used to stretch and recreate the part of my upper lip that was removed. I am still reviewed regularly to ensure there is no recurrence.
61. Although I no longer have Haemophilia, I still have problems with my previous target joints (both ankles and right elbow) due to arthritis. I get days when my joints become stiff and can freeze up and become very painful to move or walk on, just as they used to when I had Haemophilia.
62. For a period of time I had to go to the GUM clinic for my HIV treatment. I did not let that bother me and I did see a noticeable difference between the treatments I got there as compared to a Haemophilia centre. The GUM clinic appointments were very brief and quick, and they were followed by blood tests. Whereas, in Kent the HIV was dealt with at the Haemophilia Centre. The meetings there were a lot more detailed. In my opinion those were a lot better, and I still go there now for check-ups. I do not have Haemophilia anymore, but I do like to have my joints checked there.
63. I have been on the same HIV combination drug for 10 years now, as my HIV infection is undetectable. This is why the doctors do not want to change it.
64. I believe that my status could have affected a few medical procedures that I had. I had to have a couple of teeth extracted. Overall I did not have a problem with that other than the fact that the surgeon who was meant to treat me said that I would have to have it in a hospital because he was worried about my clotting factor levels. This was despite the fact that I said that I did not have Haemophilia anymore. I am not sure whether Haemophilia was the real reason why he did not want to proceed with the extractions, or perhaps my infections.

65. The timing of the removal of a tumour on my lip was also changed, probably due to my HIV. I was meant to be operated on in a normal treatment room, while the tumour was still relatively small; however, the doctor decided that I would have to be done in an operating theatre to prevent risk of infection to me. I was diagnosed in March 2017 but the operation did not take place until June 2017 by which time the tumour had grown significantly. I have enclosed pictures of the size of the tumour before the surgery and a photograph after my surgery WITN1541011.
66. I believe that the knowledge of my infections affected my education to some extent. I was told about being HIV positive when I was 17 years old. I struggled through my A Levels, and I did not do very well in them in the end. I believe that maybe the knowledge about HIV affected that, as I took my A Levels a year after I was told.
67. Despite my poor A' level results I was offered a place on a Higher National Diploma (HND) course at Portsmouth. This was ideal for me as my father was still living on the Isle of Wight, meaning I could live in Halls of Residence during the week, then cross the Solent by hovercraft to see my dad at weekends. I transferred my Haemophilia care to Portsmouth under the care of Dr P Green.
68. I kept myself to myself at university and I only had one or two close friends. I found it really difficult to socialise with others, partly down to the fact that being at Treloar's was very institutionalised so I never went out of the grounds very much, and partly because I didn't want to get close to people as I didn't want to have to tell anyone about my HIV status. I could not get around as easily as others since ongoing bleeds into my ankles were beginning to affect me more.
69. My father died in GRO-C 1989 but fortunately I still had family support from my sister who had moved to Portsmouth the year before. I did well in my exams and passed the HND with flying colours. I transferred straight onto the second year of a Mathematical Sciences degree course and spent the next two years completing the degree. I found it much harder but threw myself into it. I

finished up leaving with a 2:2 honours degree in July 1991. By this time, I had told a couple of close friends about my HIV status and they were very supportive.

70. I decided to remain in Portsmouth after finishing at university. My sister and I had inherited our parents' bungalow on the Isle of Wight, so we decided to sell it and get our own properties in Portsmouth.

71. Up until this point I had no work experience at all, so I enrolled on a training scheme. From this I got a work placement at P&O Ferries in Portsmouth. I did this for a year then they took me on directly as an employee in their IT department from April 1993.

72. I had regular reviews at Portsmouth Haemophilia Centre, which mainly involved just a brief chat followed by a blood test. In 1993 I was given a bottle of AZT and told to start taking it. I don't remember much discussion about how much the virus was affecting me. I had accepted that I had it but hadn't really noticed if it was affecting my day to day life. That is until September 1994.

73. I had noticed that I was starting to have trouble breathing. It was becoming painful and my breathing was getting shallower. I finally went to the GP and was sent straight to hospital. I was diagnosed with Pneumocystis Pneumonia (PCP) and placed on numerous drugs – steroids (Prednisolone), Co-Trimoxazole (Septrin which gave me a *'ready break glow'*) and numerous others to fight the infection and bring my CD4 level up. I also needed regular oxygen and nebuliser sessions. I was placed on an isolation ward, which felt like a porta cabin in the middle of nowhere on the East Wing of St Mary's Hospital, Portsmouth. At this time, I felt like I was going to die and I think the doctors did too, but I was determined to fight it.

74. I was in hospital for about 3 weeks, and then was able to go home with numerous drugs to take, including the nebuliser, which was very toxic. When using it, I had to seal the room I was in and open the window. The drugs made me feel terrible: nauseous, bloated and tired but I was determined to

get through it. I did get better and returned to work in November. It was only at this time I realised that PCP was an AIDS defining illness.

75. I was by then being seen regularly at the GUM clinic at St. Mary's Hospital in Portsmouth under Dr J Tobin, Consultant GU Medicine Department, who kept a much closer eye on my health and over the next few years kept changing the drug combinations I was taking to try and improve my CD4 count.

76. Time went on and in 1995 I got promoted to a different department at work. In October 1998 I noticed that one of my testicles had got much larger than normal and I was referred to the Oncology Department at St. Mary's Hospital, under Dr D J Boote, Consultant Radiotherapist & Oncologist. Within 2 weeks, I had an orchiectomy (removal of testicle). I understand my CD4 count was still very low at this time (less than 10). It was later confirmed that I did have a seminoma. I was given 2 weeks of radiation therapy from 7 until 18 December 1998 which I was able to tolerate pretty well and returned to work.

77. My HIV combination therapy had been changed several times over the years until 2001, when they finally hit on a new combination that improved my CD4 and viral load dramatically.

78. My social life was impacted by my illnesses. I was always a personable kind of individual, but Treloar's was very institutionalised and we rarely were out of the school grounds. When I went to the university I found it harder to socialise with people as a result of that. On top of that I had HIV to contend with as well. Most of the time I kept myself to myself; I was not somebody to go out drinking. It was a rare thing for me to do.

79. There was a greater impact on my relationships as I did not want to have girlfriends for a very long time, as I was too afraid of the risk of infecting them being too high. I had met a few women that I got to know online, but they remained good friends, nothing more. Regardless of whether there was any chance of a relationship or not, I felt I needed to reveal my HIV and Hepatitis C status before anything happened. Most were shocked but were sympathetic. I did see a few people but I never started seeing anybody before

telling them about my conditions. I did not want to broadcast about it, but also wanted to make sure that whoever I would be seeing could handle it. Therefore, I only told them when I knew that there was a chance of a relationship.

80. I met Tracey (my now ex-wife) online in March 2006. Tracey had 4 children of her own at the time. I was on the road to recovery and my existing house was too small to accommodate the children. My pay at the time was £33,500 and I had worked quite a lot in the last years there. I was the only one with all the knowledge and experience in the different ports, so the company needed me. In **GRO-** 2008 Tracey and I decided to move into a bigger house and get married. I bought a larger house which cost £200,000 with a mortgage.

81. Despite looking much better after my transplant, over the next 6 months I was still getting very tired and was often falling asleep at my desk, which resulted in several trips to the company doctor. Then in July 2008, the company decided that they were going to make both my original position and the position of the line manager who took over the running of both sections redundant, then create a new, different permanent position and combine both sections into one. It was basically a position that was a straight fight between the two of us being scored by other heads of department. It came as no surprise to find that the other line manager got the job; she had already been managing both sections for 2 years, and I obviously had not returned to full health. I was therefore made redundant at the end of October 2008, after a total of 15½ years' service.

82. I feel that had I not been ill enough to need the transplant in the first place, the possibility of combining the two positions into one would never have occurred and I would have been able to further my own potential.

83. I also had issues getting mortgage protection, as companies would not take me on specifically because of my conditions. Only 6 months after buying the larger property I was made redundant. I was not expecting that at all. I was faced with the prospect of having a new house with a bigger mortgage and no job. If I had known that this would happen then I would not have moved.

84. The redundancy payment managed to keep the roof over our heads in the short term, but over the following year, my marriage began to suffer because of the pressure of having no decent regular income.
85. In September 2009, Tracey moved into her own rented property in Ramsgate and I put my house on the market. However, I had bought the house just before the financial crash of 2008 and a year later it was worth £50,000 less, meaning there was not enough equity to pay off the mortgage and a loan secured against the property. I got into more and more debt, and in March 2011, the house was repossessed.
86. After my home was repossessed I moved into Tracey's rented property and we tried to make the marriage work, but in the end, we decided to part ways and I moved into my own rented property in April 2013. We got divorced the following year.
87. I believe that the financial problems were part of the reason for my marital problems. When we first got together I had agreed to take on her children as I was able to afford a family at the time. However, when money started to run out, it started to take a toll on our marriage; also the children became a lot harder to manage. It finally got to the point that Tracey felt like she wanted something more than I could provide, because I had no money coming in and we were living on benefits. Our personal life suffered as well, as we spent very little time together and we were lacking the closeness that was there once. Tracey eventually decided to move out to her own property.
88. I still have about £100,000 of debt and historic debts from over 6 years ago. If I was still working, I do not think that I would have had to take out some of those debts in the first place and others would already be paid off.
89. This was all around the time when I was diagnosed with Burkitt's lymphoma and had my chemotherapy for it. I had a call from my landlord just after I came out of hospital to tell me he was selling the property I was in. Fortunately, Tracey agreed for me to move back into her property. In 2016 Tracey moved

to Wales, leaving me to live in the property in Ramsgate. However, we have stayed in contact and we remain good friends.

90. I would not say that I have experienced any stigma in the past, but that is mostly because I did not tell many people about my infections as I kept them very private because I did not want to be treated any differently. The thought of stigma was always at the back of my mind. I have told my close friends about my status more recently.

91. My employers and the Human Resources staff knew that I had this condition but even though I was quite close with people from work I never told them about it. All I told my colleagues was that my liver was damaged and the way that I worded it was that my immune levels were low, not that I had HIV. I was very deliberate. I was not lying but I was also not giving a straight answer.

92. My work colleagues only found out about my status from a newspaper, exhibited with this statement as WITN1541012. Some of them asked me whether I had it while we were still working together, but overall they were very supportive.

Section 6. Treatment/care/support

93. I never had any issues getting a treatment. There was a delay in my transplant but it was because I was waiting for a donor, rather than funding.

94. I was never offered any counselling. I am not sure how helpful it would be, as my attitude was and still is always to get on with things and not to let things get to me.

Section 7. Financial Assistance

95. The first payment I received was £20,000 ex gratia payment from the 1991 litigation. This was also when I was first made aware of the Macfarlane Trust. I then applied to Macfarlane Trust and received a payment of £23,500.

96. I later found out about the Skipton Fund through the combination of the Macfarlane Trust and Dr Winter, who was a trustee at the Macfarlane Trust. I applied and received the stage 1 payment of £20,000. After my condition deteriorated, I received the stage 2 payment of £50,000. The timing of the Skipton Fund lump sum payment was unfortunate as I received it a month after my house got repossessed (March 2011); had it turned up a month earlier, my house could have been saved.
97. When I was suffering financial hardship in 2010 and 2011, I tried to apply for help from the Macfarlane Trust; however, they would not help with my mortgage or debt repayments. The best they offered me was to contact someone from the Terrance Higgins Trust, who duly visited, but could not help me either. My experience with the Macfarlane Trust was that they would not consider anything until every other possible avenue was explored with other organisations first. The whole process was just so degrading.
98. I currently receive money from the England Infected Blood Support Scheme (EIBSS). The transition to the EIBSS has been trouble-free for me in terms of the regular payments but having heard the experiences of others trying to get one-off payments, it seems the culture is exactly the same as the Macfarlane Trust was.
99. I used to receive monthly payments from Skipton Fund and Macfarlane Trust of about £1,836, and I was near the top level of the discretionary top-ups of £362 per month. I am now meant to go on a new monthly rate based on £44,000 per year from July 2019 onwards.
100. I do not recall dealing with any pre-conditions or obstacles. When I was first applying; Dr Winter sorted out the medical side of the application.
101. I do recall that the Macfarlane Trust required quite a lot of information, particularly for the discretionary payments. It also took into account the money from the Skipton Fund, as part of my income, which I think was wrong. This has not been happening since EIBSS. I also think that it was wrong for Housing Benefit to be taken into account, as this was not money to live on, but

went directly to the rent; not a disposable income. Therefore, it should not be looked at, as an income. I believe that the only thing that should be taken into account is the Income Support and Employment and Support Allowance (ESA). Even EBISS takes into account Housing Benefit and Council Tax Support.

102. Also some of the trusts and funds looked through all your expenditure, which I do not believe should be any of their concern. While I have not had issues with the trusts, I am aware from personal experience that my friend Su Gorman has had difficulties and will be happy to elaborate on these with the Inquiry if requested.

Section 8. Other Issues

103. As a result of being infected with contaminated blood products I have lost my job, my home, my wife, my ability to have children, the possibility of a decent pension, life insurance, my future earnings potential, had numerous serious health issues and who knows what other health condition could be yet to materialise. Ironically, the only thing I have gained is the cure for Haemophilia; the very condition whose treatment caused all the problems in the first place. Having said all that, at least I am still here, against all the odds, trying to live my life in the best way I can.

104. I became involved in Tainted Blood and campaigning from 2016 and can expand on this separately if required.

105. I believe that when it comes to compensation, it is important to take into consideration how much money everybody lost over the years and how much they could have been earning, as well as their personal losses. I got myself into debt because of losing my job, which would not have happened if it was not for my infections. It has not officially been confirmed that I lost my job because of the illnesses I have, but I believe that if I had not been ill, it is unlikely that I would have lost my job.

Anonymity, disclosure and redaction

106. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

107. I do wish to be called to give oral evidence.

Statement of Truth

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

Signed..... GRO-C

Dated..... 11-09-2019