Witness Name: Joseph Paul Peaty
Statement No: WITN4607001
Exhibits: WITN4607002 - WITN4607030
Dated: 08 September 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JOSEPH PAUL PEATY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 22 January 2021.

I, Joseph Peaty, will say as follows: -

Section 1. Introduction

1. My name is Joseph Peaty. My date of birth is GRO-C 1965. I reside at GRO-C GRO-C. I have a small immediate family, which consists of my mother, father, and younger sister, brother-in law and nieces. I am currently medically retired. Before this, I was employed by my local authority's education department, initially in their Planning and Research office but ending my employment within a secondary school in a finance, administrative and office management role.

2. I intend to speak about my infection with HIV, Hepatitis C ("HCV") and Hepatitis B ("HBV"), Hepatitis A ("HAV") and potentially vCJD, after having received contaminated blood products as treatment for my haemophilia. In

particular, my life with and without treatment, the nature of how I had learnt about my infections, how my illness has affected me and my family thereafter, the treatment I have endured, the resulting affects and the financial assistance I have received.

3. I also intend to discuss my participation in a number of clinical trials whilst I was a student at Lord Mayor Treloar College ("Treloar's") between 1979 and 1984.

4. I can confirm that I have chosen not to have legal representation and that the Inquiry Investigator has explained the anonymity process to me. I do not wish to be anonymous as I wish for my story to be known in full. That said, I do refer to an ex girlfriend in this statement, albeit I do not name her. In my **Exhibit WITN4607026,** on documents marked **T 30 January 1997** and **T 12 January 1990** her details are recorded. I respectively request that her name and address is redacted.

5. I do wish to acknowledge that there are areas of my witness statement which will need redaction, as they refer to personal details of other people, of which, they reserve the right to anonymity.

6. The Inquiry Investigator has explained to me the 'Right to Reply' procedure, and I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.

7. I have constructed this statement with limited access to my medical records because some have either been reportedly destroyed or lost or have information missing. I have referred to a database of information I collated about my medical records from information I could obtain, and to diary entries my mother made at relevant times.

   I have referenced previous publications about my story produced for the "Haemophilia and HIV Life History Project" undertaken by a team, led by Sian Edwards, from Brighton University in July 2004, which is now held by the

sound archive of the British Library, and articles including those for Novo Nordisk's "Buddies" book in 2013 and Tainted Blood's "Stories Behind the Statistics" booklet produced in 2015, besides my own and my parents recollection.

8. I also referred to my witness statement provided to the Archer Inquiry in 2007 which is twenty pages in length. In addition, in 2015, I had written a personal statement for the Haemophilia Society entitled "*Joseph's story: 'Haemophilia treatment is safe and really effective now, so why are you still campaigning*?" This published document is nine pages in length. I refer to both documents throughout my witness statement for the Infected Blood Inquiry ("IBI").

9. My aforementioned written personal statement provided to the Haemophilia Society in 2015 was copyrighted. I have provided the necessary permission to the IBI for the use of this document in my statement.

10. As you will see, my story is a long one. I have attempted to provide significant detail in order to give the IBI a comprehensive understanding of living with a very severe haemophilia condition at a time when very limited treatment options, and for a substantial part of my childhood no treatment, was available. I have discussed this with the investigator and we have been working on this section for over three months, we have agreed to complete this part of my statement now **(Part 1)** and complete the remaining section in the next couple of months.

11. I have to consider my wellbeing in this process and "slowly slowly' is the mantra I have adopted. Therefore, my statement will be told in two parts. **Part 2** will follow at a later date.

PART 1

Section 2. How Infected

Haemophilia Diagnosis

12. On GRO-C 1965, I was born at home in GRO-C Warwickshire, into a family with no previous history or experience in bleeding disorders.

13. From a young age, my mother came under scrutiny by our General Practitioner ("GP") Doctor GRO-D at GRO-D and at a postnatal welfare clinic that was attended. (This surgery has since evolved into GRO-D, GRO-D). Doctor GRO-D had noticed that when attending face-to-face consultations, I would frequently have various bleeds and bruises over my body.

14. Worried for my safety, Doctor GRO-D and the Welfare adviser challenged my parents about the reasons for my injuries. My mother became concerned that they might be considering getting Social Services involved instead of taking her request seriously to do tests that would identify the true cause. However, after a serious leg bleed when further investigations had been required, it was quickly realised that my injuries were not attributed to foul play, but instead, possibly haemophilia related.

15. Doctor GRO-D's attention had previously led to an investigation into the true cause of my regular injuries. He took a whole raft of blood samples from a vein in my arm for testing but the results appeared normal. However, two weeks later when my mother sought help for a new severe left leg bleed that was extremely swollen and had bruised from my groin down to my foot, Dr. GRO-D attended me at home immediately, and arranged for me to be rushed by ambulance to Gulson Road, Hospital, Coventry, where I could be monitored and further tests undertaken. The following morning when my mother visited me, in addition to the leg bleed, she noticed immediately that I

had a new bleed, swelling and bruising in my neck that ran down across my chest. My mother was distressed by this discovery and a nurse on duty quickly took her aside to explain a doctor (name unknown) had taken blood samples from the carotid artery in my neck and this had caused a dangerous bleed. The doctor's decision to take the blood samples from such a risky area was in spite of his belief of my suspected haemophilia diagnosis, and the knowledge of the dangers of serious bleeds. (The doctor was presumably a general paediatric doctor based on the ward as my father forbid him from caring for me further, after which my parents don't recall seeing him again.)

16. When my mother, and later my father, had challenged the doctor directly as to why he choose that location and not my arm he commented that it was his preference and decision.

17. On 28 August 1966, aged GRO-C months old, the results of the blood tests had returned. As a consequence I was diagnosed as having had a spontaneous gene mutation, causing severe haemophilia A with 0% Factor VIII level. My mother wasn't provided with this definitive diagnosis until I was around 14 months old, apparently because the doctors had wanted to recheck results once I was over 12 months of age.

18. My mother had no suspicion that she might be a carrier of haemophilia. Unfortunately, we were unable to look fully into our family's medical background as my mother's mother had left their family home when her three daughters were young and had not maintained contact. Therefore, we were unable to confirm as fact that haemophilia ran in my Grandmother's side of the family. There was no known history in my Grandfather's side so as far as is currently known, there is no family history of haemophilia; I am the first.

19. My parents were told very limited information about my haemophilia by Doctor GRO-D other than I should not bump or cut myself as I wouldn't stop bleeding normally. There was no mention of support information or organisations. They were thrown into the deep end and felt totally isolated. I can only assume that this was due to my diagnosis having taken place in an era where there was no

information or significant support, even from a Haemophilia Society that was still young and heavily reliant on the advice of government bodies.

20. Due to the limited information provided to my parents by Doctor GRO-D, and the fact that there was no experience to draw upon in the family, my parents struggled with learning how to effectively understand and manage my haemophilia without having been properly informed. In addition, when I attended the Birmingham Children's Hospital, Steelhouse Lane, Birmingham, B4 6NH, for treatment, consultations or admission, we rarely came into contact with other haemophiliacs. I feel now as though the hospital intentionally kept us apart. This made it equally difficult for my parents as they could not ask other parents for advice on how to effectively manage my haemophilia.

21. Following my haemophilia diagnosis in 1966/67, my mother was later visiting me in Birmingham Children's Hospital when the consultant doctor caring for me advised her that she should have no further children because of the associated risk that her next child might also be born with haemophilia. However, my mother was already pregnant with my sister at that point.

22. After my sister was born on GRO-C 1968 my parents took the decision not to have any further children despite it always being their intention to have a larger family.

23. GRO-C

24. GRO-C

GRO-C

25. My gene test in 2000 confirmed that I have an Intron 22 Inversion (more commonly known as a "*Flip tip inversion*") resulting in Haemophilia A. This occurs when the Inversion causes two abnormal A genes, both of which fail to produce Factor VIII when transcribed.

Treatment for Haemophilia

26. For the first year after my haemophilia diagnosis in 1966, I was not provided with any treatment for my haemophilia. My parents were instead advised by the doctors at Gulson Hospital ("Gulson"), Gulson Road, Coventry, CV1 2JH, to protect and prevent bleeds where possible. When bleeds occurred, they were advised to treat with rest, ice packs and pain relief.

27. Thereafter, from 1967, when I was aged 20 months, the majority of my bleeds were still treated by rest, ice packs and analgesics alone, but I began to be treated with cryoprecipitate via a drip infusion for the most severe internal joint, muscle and soft tissue bleeds as well as rest. For life-threatening external bleeding I received both Cryoprecipitate and whole blood transfusion.

28. On the evening of 29 July 1967, my parents encountered their first serious test as parents of a haemophiliac. While visiting with my parents, I suffered a fall in my grandmother's home, knocking my mouth in the process. This caused a small cut to the frenulum under my upper lip inside my mouth. At seeing the extent of the blood that was coming from my mouth, my parents took me to Coventry & Warwickshire Hospital, Stoney Stanton Road, Coventry, (my parents think this was because of it having an A&E department and also it was out of hours to access doctors at Gulson Road Hospital).

29. Upon initial observations by the doctors, it was discovered that I had suffered a small cut to the fraenulum on the inside of my mouth. My parents were advised not to worry, to treat the bleed by washing my mouth out with warm water and to take me home and put me to bed to rest. Looking back now, the warm water treatment would have magnified the bleed not stopped or slowed it.

30. At 7.30 the following morning, 30th July 1967, alarmed by the amount of bleeding overnight my parents rushed me to Gulson Road Hospital. Doctors initially insisted on trying to stem the bleeding by packing the mouth with swabs and Oxygel, and putting me onto iron supplements in case of anaemia, but by 11am agreed to my mother's pleadings for them to seek more expert advice. Arrangements were then made for my transfer to Birmingham Children's Hospital to the care of Professor Hubble & Medical Registrar Dr. Jillian Mann.

31. On 30 July 1967, my mother recorded that I was given Cryoprecipitate via a drip infusion for the first time as well as a transfusion of 4 pints of whole blood during their attempts to stop the bleeding. A medical note summary shows I received 1 unit of Cryoprecipitate per day for 6 days and, initially, packed red cells from one pint of whole blood. I was discharge on 05 August 1967.

32. On 07 August 1967, my frenulum had started bleeding again. My parents returned me to Gulson Road Hospital where I was transferred by ambulance to Birmingham Children's Hospital once more. Treatment with one unit of Cryoprecipitate per day via a drip infusion was re-commenced, but on the 11 August, with bleeding stopping and then restarting 12 hours later and my haemoglobin dropping again, another transfusion with packed red cells was required and treatment with Cryoprecipitate was increased to 2 units bd. Despite my young age, I recall the trauma of being tied to the ward bed by my hands and feet, in an attempt to prevent me from moving or touching my mouth, and of being prevented from seeing my parents. My face was stuck to the pillow due to the blood I was losing from my mouth. Cannulas were not so

advanced or flexible then and were more likely to be painful to endure and often became infected and a new one installed after a few days.

33. My parents were prevented from being able to visit me face-to-face for around ten days whilst I was provided with my treatment of Cryoprecipitate and blood transfusions, only being permitted a daily peek through the door's curtain. Despite sedation, seeing their face would make me start moving around and crying, which would open up the wound in my mouth again so doctors wanted to prevent this. My parents have spoken about this time and how distressing it was for us all.

34. The doctors decided to continue treatment for 6 days beyond the bleeding having apparently stopped on this occasion. This approach was successful and on 21 August 1967, three weeks after my injury and initial treatment, and having received substantial infusions of Cryoprecipitate and packed red cells from whole blood, I was discharged from Birmingham Children's Hospital. Factor replacement therapies were in their infancy so it came with difficulties, but they offered hope of controlling bleeds where before there was none and whilst the treatment was not pleasant, it was effective. My medical records also record my parents consent to treat me was obtained. My parents recollection is that this related to the use of Cryoprecipitate and blood, but did not include any information as to transfusion related risks.

35. This experience set a frightening scene for my future life with haemophilia and the treatments for my bleeds thereafter.

36. I would regularly experience spontaneous joint or muscle bleeds, sometimes several at once, or occasional traumatic external bleeding. Frequently they would occur in the middle of the night or at the most inappropriate moment. This meant that I would either have to manage my bleeds at home with rest, which would result in not being able to sleep for days at a time due to substantial pain, or, spent lengths of time in hospital resting or receiving treatment.

37. Thenceforth, I received treatment of Cryoprecipitate routinely for my severest bleeds, up until 01 February 1971. It was effective and I experienced no significant side effects.

38. In May 1968, my haemophilia was considered by the Health Department of the Local Authority in the context of schooling. After reviewing my medical history and consultation with Dr. Kendal at Coventry and Warwickshire Hospital, the Principal School Medical Officer, T. M. Clayton decided that I should start nursery school early, at around the age of three years old, in a local '*day school for physically handicapped children*'.

39. In September 1968, two months short of being three years old, I started attending the Sherbourne Fields Special School ("Sherbourne"), nursery unit, Rowington Close, Coventry, CV6 1PR. This was a day school for children with physical disabilities. However, no members of staff at Sherbourne had any knowledge on how to manage pupils with haemophilia or the dangers that went with it. They failed to understand the nature of my condition resulting in a number of injuries which led to serious life changing bleeds.

40. By the age of five years old, I had already spent a year or so living with a painful mouth infection and recurrent abscesses. Eventually, on 01 February 1971, I was admitted to Birmingham Children's Hospital to undergo surgery for a tooth extraction to help the gum to heal.

41. There was one unexpected problem. As the surgeons were preparing for my operation, a routine screening blood test showed that I had not achieved the expected raised clotting level. My doctor decided to carry out a blood test to determine the cause and the result showed that I had developed an antibody that was described to my parents as a high responding inhibitor to my Cryoprecipitate treatment.

42. This was disastrous news as I was due to receive Cryoprecipitate as cover for my imminent surgery, to prevent any persistent bleeding I would experience.

As a result, any beneficial effect of my coagulation therapy was substantially limited, which in effect, left me without any protection for surgery.

43. I have since learnt that around 30% of severe haemophiliacs with type A will develop an antibody to Cryoprecipitate or Factor 8 concentrates at some point during their treatment life.

44. The surgeons and the medical staff at the Birmingham Children's Hospital were all concerned as to whether my operation for a tooth extraction should go ahead, particularly given my earlier experiences when treatment had been available. The decision not to proceed was taken by my consultant, Dr. John Stuart.

45. Thereafter, Mr Doctor advised a policy of treatment abstinence in the hope that my inhibitor level would decrease.

46. Inhibitors are a significant complication for a haemophiliac and without the prospect of any treatment at that time, and witnessing me suffer from excruciating severe bleeds, mouth bleeding from teething, and the continuing problem of a recurrent abscess that required surgery, my parents naturally became much more protective; even overprotective.

47. As a child I was very boisterous but was constantly taught to look out for dangers and to protect myself. I always felt very vulnerable away from my home environment though, because my condition and its risks were so poorly understood.

48. Unbeknown to my parents, or myself I was also tested in February 1971, and found to be positive, for Porcine and Bovine Factor VIII inhibitors despite my parents having no knowledge of such products being used to treat my bleeds previously.

49. One occasion my parents' recall demonstrates how this may have occurred.

50. I had been admitted to Birmingham Children's Hospital for a knee bleed and my parents were at the hospital to visit me. They arrived at my bedside to witness me being infused with something. To my mum's horror my neck and body were frighteningly swelling up and I was struggling to breathe. She was witnessing the onset of anaphylactic shock.

51. The doctors controlled the reaction and my parents learned later that the substance infused was Bovine Factor VIII.

52. My mother recalls hearing a comment from one of the doctors immediately after of something along the lines of *"oops we have already tried that one"*. This indicated the experiment had already been tried on me previously by a different doctor, but had not been recorded in my notes. Her impression was that it was because of the previous exposure that I had an adverse reaction.

53. My parents were very concerned that an experimental form of treatment had been used on me without them having been consulted or giving their consent.

54. It appears odd that Bovine inhibitor tests show a result that was markedly different in November 1971 than it was in January 1971 (high vs 5) when referring to the data held by the UKHCDO if I wasn't being exposed to Bovine products.

55. I have in my possession a letter from my consultant at Birmingham Children's Hospital and my GP Doctor GRO-D, in addition to a record from the UKHCDO/MRC which demonstrates I had Factor VIII inhibitor levels of 30 m/l Human, 15 m/l Porcine and 4 u/ml Bovine in February 1971. In retrospect, after having inspected my medical records, no previous exposure to Porcine or Bovine products has been recorded. **Exhibit WITN4607013 refs.**

56. In 1973, when I was aged seven years old, there occurred two further life threatening bleeds; both of which, in effect had been caused as I was left with no protection due to my inhibitor related treatment abstinence. Both of these bleeds were respectively treated without Cryoprecipitate.

57. The first of these life-threatening bleeds unfolded at bedtime on the 11 April 1973. It was a period where a number of things had happened.

58. I can recall being in the playground at Sherbourne during the lunch break that day when I noticed another lad around the same age as myself was nearby. I was vaguely aware that he had behavioural problems and, during an outburst he pushed me out of his way. I landed in a small tree and a branch poked me in the middle of my back. I remember rubbing the area to relieve the immediate pain but thought no more of it. The staff on duty didn't pay any particular attention to the brief incident.

59. After returning home from school at 15:45pm, I complained to my mother that my neck felt stiff.

60. Previously, around three days earlier on the 08 April, I had also walked under newly installed anti-bike bars on our local alleyway, accidentally glancing the top/back of my head. This resulted in a noticeable lump that my mother had noted before but which took on greater significance that evening.

61. By 7:15pm when I was getting ready for bed, I screamed out with pain in my back and found that I could not lie down flat because the pain was so excruciating.

62. My parents immediately drove me to Birmingham Children's hospital where I was admitted with a suspected intra-spinal bleed under the care of Dr.Insley. After initial observations by the medical staff this diagnosis was confirmed.

63. Without any treatment my condition rapidly deteriorated causing my stiff, painful neck and back to progress to a severe quadriplegia with upper motor neuron lesion signs and sensory loss below spinal segments T2-T3. I was totally paralysed from the neck down.

64. By 13 April 1973, my breathing became extremely shallow and I was moved to ITU. My mother was provided with a room in which to stay at the hospital in order to be close by even when she took a break from being at my bedside.

65. Because of my Human Factor VIII inhibitor the doctors could not treat my spinal bleed with Cryoprecipitate and swamping the antibody with very high doses of Factor VIII was not feasible due to the volume involved. Instead a course of Porcine Factor VIII treatment was decided upon and my parents waited anxiously to see if it would work.

66. My parents do not recall being included in the decision about what treatment to use or not, nor were they told of any associated risks, nor indeed about my previously identified Porcine inhibitor. In such a dire situation they trusted the doctors to take the most appropriate action and consent, as such, was given informally along the lines of saying "*do what you can.*"

67. After 5 days of Porcine infusions, I developed a very high Porcine factor VIII inhibitor, rendering further administration useless. However, the treatment I received appeared to work and I began to show signs of a slow recovery. I do not know if the product was American or British, or the brand. The use of Porcine was reported to the UKHCDO (Oxford) but product information isn't shown on the records supplied by them.

68. Thenceforth, I had a slow recovery. After three weeks of paralysis, with physiotherapy and determination, I began to get my feeling back all over my body and my nervous system started to rumble. It was my arms first, then upper body and then legs that began to regain sensation and then function. I learnt to use my limbs again and progressively, how to walk. I gradually regained my previous abilities, with just a few neurological injuries taking longer to improve. The doctors were all amazed at my recovery.

69. Due to my quick recovery, the doctors at Birmingham Children's Hospital wanted to use me as a training example for their student doctors. On a few occasions, they would wheel me from my bed into a lecture room in the

hospital where there were a number of student doctors seated. After being placed immediately in front of them, my spinal specialist Dr. Green proceeded to discuss my paralysis, treatment, and respective recovery in detail. I didn't mind this as I thought I would be helping. My mother, grateful for the doctor's part in my care, agreed informally that this was okay to do.

70. I was discharged from Birmingham Children's Hospital to return home on 4 May 1973 after a stay of 3 weeks. I still had significant damage, with some residual spasticity, loss of sensation, continence issues and the need to learn how to walk again.

71. By 08 October 1973 when Dr. Jillian Mann saw me in clinic, I was making significant progress, regaining strength, and mobility and walking fairly steadily unaided. I continued to be monitored during my childhood but later, when transferred to adult haemophilia care, no regular monitoring of the my progress was undertaken. **Exhibit WITN4607014 refs.**

72. My second life-threatening bleeding episode arose just as my recovery from the spinal injury began in earnest. The carious tooth and persistent abscess, for which surgery had been cancelled in 1971, after my inhibitor development, once again became an urgent problem.

73. I had recurrent abscesses and the affected gum around the tooth was bleeding intermittently. The infection deteriorated despite regular treatment with antibiotics and then the bleeding worsened.

74. By the time Dr. Mann reviewed me in clinic on 08 October 1973, the doctors and my hospital dentist Mr. Hoggins had decided that, despite the risks, the surgery should go ahead at Birmingham Children's hospital, without the use of coagulation therapy. Their plan instead was to use haemorrhage pressure plates and epsilon aminocaproic acid, which is a medicine that helps with the formation of coagulation.

75. Besides a brief mention on 08 March 1974 that confirms I had a tooth extracted, my hospital notes appear to be missing the details of my admission, tooth extraction and the ensuing fight to control my bleeding, so I have no official medical records to refer to about this episode.

76. Fortunately, my mother did keep a detailed record and that is what I have used to recount the events.

77. I was admitted to Birmingham Children's hospital on 6 November 1973. At that time the infected gum around my carious tooth was bleeding badly. I was vomiting the copious amount of blood swallowed.

78. By the 15 November 1973 the bleeding had not settled and the situation was deteriorating. My parents had been informed of the doctor's decision to perform surgery and extract a double tooth and smaller tooth.

79. My parents arrived at the hospital at 11.30am on 15 November expecting that the surgery should have been completed that morning. However, my mother discovered the surgery has not yet occurred and the surgeon was apparently pacing the theatre, unsure whether to perform the extraction because of the risk to my life.

80. My parents went to the surgeons office to discuss the situation and my mother had to make the decision that they carry out the procedure as planned because the gum had become so persistently infected, and painful that it was intolerable for me.

81. The surgeon eventually agreed. He performed the extractions and fitted the pressure plate. Initially, the doctors were pleased that I wasn't bleeding heavily. However, as is often the way with my bleeding patterns, I began bleeding more profusely the next day.

82. The symptoms become too gory to describe in detail here, but for weeks after I recall waking up in pools of blood, my head stuck to the pillow and frequently

vomiting from the amount of blood swallowed. My mouth was effectively wired shut so I could only manage fluids through a straw and I was on a drip for around three weeks to provide sustenance.

83. The first of many blood transfusions began on 17 November. My mother records at least 5 pints of blood were required over the coming days and doctors commented that I was losing blood as fast as it was being replaced.

84. Everyone was distressed and extremely concerned. It didn't seem as though the bleeding was slowing down.

85. On the 22 November 1973 there were the first signs that the bleeding might be slowing a little and three days later there was a noticeable improvement. By my birthday on the GRO-C I was permitted to eat. I celebrated a birthday we all thought I might not see, with cards and presents and a birthday cake in the form of an Ice cream.

86. On the GRO-C 1973, more than three weeks since the fight to survive began, I was discharged home.

87. Life returned to relative normality for a while. I had frequent bleeds that were treated at home with rest and ice packs, many pain-filled, sleepless nights and interrupted school, family and social lives. But in between the bleeds I enjoyed as full a life as possible, went to school and continued my recovery from the spinal bleed.

88. On 03 February 1975 the next life-changing event occurred that would permanently affect my mobility.

89. I was attending Sherbourne and it was lunch break. I was walking from the toilets near my class toward the reception and large playground when I saw a boy who I knew to have psychological and behavioural problems grab a girl in a wheelchair and begin pushing her around at speed against her will. The boy

often liked to push wheelchairs around and frequently crashed them. The staff supervising didn't seem able to control his behaviour or stop him doing this.

90. He chose to push the wheelchair along the corridor toward me. A friend I was with managed to move out of the way but I wasn't so lucky and he crashed into my left leg knocking me to the floor. Mrs. Harris, a teacher at the school, noticed me on the ground but the incident passed by without anyone checking on me further or completing an accident record as might have been expected.

91. By the time I was dropped at home by the school transport at the end of the school day I had a severe bleed in my left knee. My mother recorded this and my account about the incident at school.

92. This began a cycle of recurrent bleeds that wouldn't settle even with splinting. Over the next year the leg deteriorated, I lost my full range of movement and the muscle began wasting. After a bleed resolved, I would only be able to walk for short periods of time before the weight bearing would trigger another joint bleed. **Exhibit WITN4607015 Refs.**

93. After a clinic review with Dr. Kendall, a case note on 05 September 1975 reports that the injured left leg had experienced accelerated growth and I now needed a 1 ½ inch custom raised right shoe to compensate for this.

94. By 03 May 1976 my mother noted that I was using a wheelchair much of the time, and particularly at school.

95. In an attempt to reverse the deterioration of my left knee and regain the range of movement to aide weight bearing, I was admitted to Birmingham Children's Hospital from 12 May to 27 June 1978 for a course of traction. The outcome was a short-term improvement but ultimately didn't re-enable normal weight bearing.

96. Between June 1981 to September 1987 Dr. Savidge at St. Thomas' Hospital, London reviewed me several times to explore the possibility of inactivating my

inhibitor using new experimental techniques such as plasmapheresis, controlling bleeding by various methods including some that at were not licenced in the UK at that point, and performing surgery on my left knee with the aim of enabling me to walk without recurrent bleeding again. Dr. Savidge dropped the investigations when the complications of AIDS within the haemophilia community became more prominent and legal action began.

97. Thereafter, I settled on using a combination of a manual wheelchair, that I primarily pushed along with my legs, walking with crutches or hopping on my stronger, healthier right leg. I managed this without causing significant bleeding issues for either leg.

98. It is only now in 2021 that joint replacement surgery is being contemplated again, thanks to recent advances in non-blood product medication for haemophilia (Hemlibra).

99. From 19 April 1970, the date it appears I was last given Cryoprecipitate before my human Factor VIII inhibitor development was identified in February 1971, I had received only whole blood/packed red cells and a 5-day course of Porcine infusions for life-threatening bleeds, essentially missing out on the development of large-pool freeze-dried human Factor VIII concentrates.

100. It is notable, I discovered when I obtained my medical records, that Hepatitis screening was occurring from at least 7 August 1974 and on the 28 January 1977, despite receiving substantial quantities of whole blood/packed red cells and Cryoprecipitate up to that point, all recorded Hepatitis antigen and antibody tests (HAA) remained Negative. This was to change in June 1977.

101. I had resumed my education at Sherbourne. However, since the point of developing an inhibitor, I experienced more untreated severe bleeds, more time off school, and sleepless nights due to pain. Nevertheless, I would bounce back and continued to pursue a full and active lifestyle within the usual constraints that haemophilia dictated.

102. I was prevented from joining in with more "*at risk*" activities, and I had to find other "*bleed-friendly*" alternatives to do such as drawing, making Airfix models, reading, or playing snooker.

103. My parents, physiotherapists and GP decided it would be good for me to cycle to keep me active, but for safety, I should have a trike. Whilst I was grateful that I could cycle, I loved the idea of a bike as I did not want to feel any different to the other children at home who were riding bikes. So, when the trike arrived, I spent a lot of time learning to ride it on two wheels; much to my mother's horror.

104. I was regularly able to partake in my Physical Education classes at school, depending on the bleeds I had at the time.

105. On Tuesday 31 May 1977, the teacher decided my class should play a game of Rounders in the multi-purpose dining/sports hall, which had a shiny new floor similar to the type you would find in hospital corridors. This was in spite of my GP and parents advising that if I was to play sports at school, I could do, but only on soft surfaces such as grass.

106. When it was my turn to play, I was encouraged to get out of my wheelchair so that I could stand to play. As I neared the last base to complete my go, I placed my weight on my weaker, damaged left knee in the same way as I had been doing. However, my leg must have given way and I suddenly fell to the ground and hit my head hard on the floor.

107. I was knocked senseless and I was semi-conscious. I can recall having glimpses of being conscious one minute, then unconscious the next. In an attempt to provide me with medical assistance, the staff at Sherbourne moved me to the nurse's room where my condition was assessed.

108. Thereafter, instead of ringing for an ambulance, which would have been the obvious option due to the condition of my health, or attempting to seek advice from my mother or GP by phone, the staff decided in their wisdom to

put me on the school transport at the back of the bus to take me home. To make matters worse, I was the last drop off.

109. As the school transport reached my home, around two hours after my initial accident, my granddad who was visiting, met the attendant and guided me inside the house. My mother, who had been talking with a neighbour about preparations for the upcoming Silver Jubilee street party, came back to the house to discover me sat inside holding my head with the pain and in a very confused state. The attendant explained I had had a small knock on my head but that 'I was fine'. This didn't seem to accord with my mother's observations. The Sherbourne Head Teacher Mr. Murphy then arrived outside our home. My mother recalls he was as white as a sheet which I can only attribute to the fact that he knew the school had messed up, not only in allowing me to take part in a sport on a hard surface but particularly by not calling an ambulance immediately.

110. Sherbourne's Head Teacher asked what he could do to help then personally took my mother and I to Birmingham Children's Hospital for medical assistance. Here, I was diagnosed with concussion and admitted for observation under the care of my haemophilia specialist Doctor Mann. Presumably because of my Factor VIII inhibitor, no treatment was administered at that time beyond the observation for signs of a cerebral bleed. **Exhibit WITN4607016 refs.**

111. On Thursday evening of 02 June 1977, my mother recalls I was still experiencing headaches, nausea, and fatigue, which were obvious continuing signs of concussion. Despite this, I was considered well enough to be discharged from Birmingham Children's Hospital to return home. My mother was concerned about this decision, but as it was at the advice of my doctor, she did not challenge her.

112. On the night of Friday 03 June 1977 my mother was still worried about the state of my health; I was still experiencing a severe headache, nausea and had vomited a number of times through the night.

113. On Saturday 04 June 1977 she telephoned Birmingham Children's Hospital to explain my symptoms, her concern, and that in the grand scheme of things, my health was still not right. She was advised to bring me back to the hospital.

114. I was admitted back into Birmingham Children's Hospital in the afternoon of Saturday 04 June 1977. It was only at this point upon my second admission to hospital that I was given a head x-ray to determine if there were any obvious signs of injury.

115. On Monday afternoon 06 June 1977, with me drifting in and out of consciousness, arms extending and flailing, legs stiffening, and back extending during fits, Dr. Mann decided to give me my first massive dose of Factor VIII. It appears to have been too delayed and despite two further infusions the next day, my condition continued to deteriorate.

116. My mother was desperately concerned that the doctors at Birmingham Children's Hospital weren't experienced in treating my type of injury and that the care I was receiving was insufficient. Witnessing my deterioration she asked if there was anyone else who could provide greater medical expertise. Thereafter, Dr. Mann made arrangements and I was referred to the care of Dr Charles Rizza Consultant Haematologist and Mr. C. Adams Consultant Neurosurgeon at John Radcliffe hospital ("John Radcliffe"), Headley Way, Headington, Oxford, OX3 9DU.

117. On Tuesday 07 June 1977, a week after my original head injury, I was given a further dose of Factor VIII at 4.30pm then transferred to the John Radcliffe in a semi-conscious and deteriorating condition that evening.

118. When I was transferred to the John Radcliffe from Birmingham Children's Hospital, I was taken by ambulance and told we would need to meet a police escort on route too when we changed jurisdictions. However during the journey, which would usually take around an hour and forty-five minutes, we

had to stop on at least two separate occasions. On one occasion, when we entered the jurisdiction of Oxfordshire, we stopped to wait for the police escort for sometime but when it didn't materialise my mother implored the driver to continue without it, which he did. Another occasion was due to one of the ambulance crew being travelsick. When I eventually reached the John Radcliffe some time after 10pm, the medical staff were standing waiting for us, concerned at the length of time our delayed journey took.

119. I was immediately whisked away to theatre for a specialist type of scan; a carotid angiogram that was performed under massive Factor VIII cover. My parents had to provide written consent for surgery to evacuate the expected haematoma that was planned for the conclusion of the scan. However, the scan did not show the massive bleed expected and instead the diagnosis suggested was a small contusion in the brain stem. The only treatment advised was for my haemophilia and the surgery was cancelled.

120. The next day, as I lay unconscious in a side room, somehow I vividly recall the sounds of a Punch and Judy show happening on the main ward and a conversation my father was having about it with my nurse. It had been arranged specially for the Queen's Silver Jubilee celebrations I heard.

121. Over the next week Dr. Rizza managed my haemophilia treatment. I received Factor VIII regularly but I do not know the details of frequency, dose or product used as these details are missing from the medical file provided to me by John Radcliffe Hospital. When I became conscious and alert again around three days later, I do remember one infusion by Dr Rizza where he described the treatment he was infusing into my arm as a golden product from America, the best of the best, and that I was a very luck boy to be getting it. I did feel lucky.

122. When I phoned the John Radcliffe more recently and questioned why my treatment details were missing from my file the records clerk could not tell me but did manage to help me obtain information about which brand of product it would have been. I was told the product would have been sourced

from Baxter in America. However, I have since discovered from the UKHCDO NHD records that between the three doses received at Birmingham Children's Hospital and the remaining therapy given at John Radcliffe, I received Travenol, Hyland and Hemofil products that year. This was the only bleed treated with Factor VIII so the records must relate to this occasion.

123. When I was given Factor VIII, neither my parents nor I were notified of any downsides or the risks associated with the blood product by Dr Rizza. My parents were naturally lacking the information to contribute to a fully informed decision. Dr Rizza was very positive about the new imported Factor VIII. My parents, facing a dire situation, were entirely guided by the doctor's recommended treatment when providing any consent. They were none the wiser, and any immediate fears they had were soon relieved as they started to notice that the treatment was working. My condition began to improve slowly after three days and the headaches and severe photo phobia took around ten days to cease, but by discharge on 07 July 1977 I had made a good recovery.

Other Infections - Hepatitis

124. At the beginning of July, around 28 days since my first Factor VIII infusion at Birmingham Children's Hospital and about 14 days since my last infusion at John Radcliffe, I was being prepared for discharge from the John Radcliffe, when I noticed that my urine was dark brown in colour, and that my stomach had become enlarged beyond normal size; it was protruding in nature. This was very out of the ordinary for my usual complexion and body size.

125. One day, after my progress had been assessed by Dr Rizza, I asked him why I was like that, and in a very flippant and off the cuff manner, he said *"oh that would be the hepatitis"* At a very young age of eleven years old, this was a hard thing to comprehend. I looked and him quizzically and said "*hepatitis where would I get that from*?" to which he replied "*oh that will be the treatment, it's full of it. There is nothing to worry about, you will get over it.*"

126. In those days, doctors were figures you did not question, as you would otherwise do in this day and age at the date of writing this witness statement. We took Dr Rizza at his word, and did not mention it again to him.

127. My mother did mention her concerns to Dr. Mann who wrote to Dr. Rizza on 12 August 1977 after reviewing me in clinic that day. Within her letter she raises the possibility that I had a 'mild dose of serum hepatitis' following treatment with Factor VIII concentrates and highlighted that my spleen was palpable on examination. Dr. Mann also confirms that she has arranged liver function and viral studies but felt treatment was not required as I no longer exhibited acute symptoms. Dr. Rizza replied to her letter on 24 August 1977 in the briefest of terms stating simply "We are all delighted to hear that Joseph is continuing to do well".

128. For Dr. Rizza to have made such a bold statement at the time is suspicious. Did Dr. Rizza know whether or not this "*golden product*" was being virally screened and donors carefully selected or, did he understand that it was not safe? By stating "you will get over it", did he know for certain that getting hepatitis would not be harmful in the short or long term? Was he aware that there were types other than A and B? Why was he not interested in following the incubation time which may have provided a clue to the type of viral hepatitis? Why did he not test for Hepatitis A as well as B thus allowing a potential diagnosis of non-A non-B to be made?

129. The remark made insinuates that Dr. Rizza was fully aware of the risks of blood borne viruses such as hepatitis associated with Factor VIII treatment prior to the point of administering it to me as treatment.

130. Furthermore, laboratory tests on my blood requested by Dr. Rizza on 20 June 1977 and 1 July 1977, to check for the presence of Hepatitis B antigen and antibody, confirm that he was aware of the viral risk associated with the treatment. Curiously, no such test was requested after my mother informed him of the symptoms he had associated with hepatitis. Was this because he

had already discounted Hepatitis B and assigned it as Non-A Non-B hepatitis (later designated as type C)?

131. At no point, were the possible risks of any blood borne viruses associated with treatment with blood products explained either to my parents or myself, so that we could have made an informed decision.

132. Dr Rizza at the John Radcliffe, and prior to that Dr. Mann and Dr. Hill at the Birmingham Children's Hospital should have sat my parents down and said something along the lines of *"we have one treatment which would help with treating your son's bleed, but, it has some associated risks of infection. If we do not treat him with this factor concentrate, he may become very ill, or even die but if we do he may become ill later and possibly suffer liver damage."*

133. It should have been about giving my parents the right information for them to have been able to make an informed decision on whether to risk the dangers of contracting a blood borne virus or risk the effect of the bleed if I was left untreated. A parent faced with this information would have found it an extremely difficult thing to hear, but it needed to be done. The doctors should have just been honest with my parents from the outset and told them of the risks associated after which they could have supported them in arriving at a decision.

134. The irony of it all, was that Dr Rizza was right in what he said, the Factor VIII treatment was a life saver. It does great things, and I thank the NHS for the chance to have received this treatment as it did, treat my cerebral bleed when I most needed it. Even had informed consent been sought the likelihood is that I would have needed the Factor VIII to survive and my parents would have agreed to it being used as a last resort.

135. That dilemma could have been rendered unnecessary. Had concerted efforts been made to virally inactivate the product much earlier. This wonder drug, that carried with it the certain risks associated with contamination with blood borne viruses, and in turn their life threatening risk, was made safe very

quickly in the mid-1980's. Why, when techniques were already well understood, and already applied to blood products such as Albumin, was it left until then to invest in techniques that could make the product safe?

136. My experience cuts to the heart of the early use of this human factor concentrates. It raises serious questions as to why such a wonder drug had not been evaluated and made safe before licencing and widespread use had been granted for non life-threatening bleeds and prophylaxis where the balance of risk to benefit would certainly have swung toward not treating, unlike the dire situation my parents were faced with.

137. I later learned why the risks of using blood products, and in particular American commercial blood products, were so high. Other than viral inactivation, the most impactful way of making the product safe is by strictly controlling donor selection, screening, limiting pool sizes, and deferring product use until donors were reassessed (in case they were in an early infected state that would not get identified by initial screening). Unpaid donors were considered to be a safer donor population unlike the American commercial donor market where blood came from paid donors with a higher likelihood of being infected and desperate to obtain money to survive or feed a drug addiction. Donor selection and screening in America proved not to be rigorous enough and product pool sizes were larger than those employed in the UK, particularly if compared with cryoprecipitate use.

138. With the knowledge I have gained since, I feel if a British product had been available then, and it employed rigorously the selection criteria outlined above, I need not have been exposed to such a high viral risk and may not have been infected. Dr. Rizza, being a prominent and informed clinician, I believe should have known this.

Previously Untreated Patient ("PUP")

139. When I first inspected my medical records in the 1980's HIV litigation I did notice that on the inside cover and a number of pages relating to my

haemophilia treatment "PUP" was written. As Dr. Rizza was my primary haemophilia-treating physician at Oxford I believe he must have been responsible for the references. I have retrospectively learnt that this reference stands for "Previously Untreated Patient." I find it shocking that I should have been identified this way and am suspicious as to what the purpose of the reference could be.

140. When I first understood the reference "PUP" written on my medical notes, I tried to be generous and understand whether it would serve any beneficial purpose for my immediate treatment at that time. However, in reality, I cannot comprehend what other purpose this would serve besides notifying someone analysing my records that I had not been treated with human Factor VIII concentrates in the past, prior to the cerebral bleed. It was a curious thing to flag up on a person's medical record. Why was it necessary to make this distinction clear to the medical professionals at the John Radcliffe who were looking at my medical notes? Why was it relevant?

141. This made me think. Did these three capital letters mark me as someone who could be usefully studied? I was suspicious as to whether a certain doctor such as Doctor Rizza, may have been actively seeking people such as myself, who were previously untreated persons of commercial human factor concentrates.

142. Even if he was not actively seeking out previously untreated patients to trial with factor concentrates, the question has to be asked, was he looking for opportunities in which he could justify providing factor concentrates as treatment, and then studying the results?

143. Alternatively, was this a warning to clinicians to be vigilant because Dr. Rizza knew commercial Factor VIII carried undisclosed viral risks that could pose acute dangers, particularly in a newly exposed patient? Were non-consensual viral screening tests carried out for Hepatitis B evidence of this?

Identifying Suitable Schooling

144. After recovering from the cerebral bleed, discussions were held with the local education authority about my return to school. Given the circumstances of my injuries while in their care my mother was adamant that I should not go back to Sherbourne.

145. With no obvious solution I was placed on home tuition and between 1977 and 1979 received two hours daily tuition at home on a one to one basis.

146. Initially assessed as being substantially behind in my education, because of all the lost schooling due to bleeds that needed to be rested, over those few years my tutor and I more than covered the lost ground and put my education back on track.

147. Throughout this period, 1977-1979, I was still treating my regular bleeds conservatively with rest and abstinence from blood products.

148. In 1978 the local authority again wanted me to start attending Sherbourne. My mother initially agreed to me trying a couple of afternoon sessions per week. However, in the end, neither my mother nor myself were happy with the arrangement or the prospects of a full time return. My mother felt the School was inappropriate and was adamant there was no way I would be going back there.

Lord Mayor Treloar College

149. In February 1979 my parents were still grappling with the dilemma of how my education could be best met. The local authority was not happy to continue with home tuition and wanted me to attend full time school again.

150. It was around this time that my home tutor, Mrs. Pat Llewellyn, mentioned talking with Mrs. Lena Crockett that worked for GRO-C local authority. Mrs. Crocket described a boarding school where haemophiliacs were able to

attend and receive support for their medical needs; she had apparently worked at the school in her earlier career.

151. This was the first we had ever heard of Lord Mayor Treloar College or in fact any school that catered for the needs of haemophiliacs.

152. My mother immediately contacted the local authority to seek further information, and ask why the school had never been mentioned before. She was told it was because they thought I was too severe.

153. At my next haemophilia clinic with Dr. Hill, on 12 January 1979 at Birmingham Children's Hospital, my mother asked if he knew of Treloar's. To our surprise he and Dr. Mann were already well aware of Treloar College. I asked about the possibility of going there and Dr. Hill agreed to contact the haemophilia centre director, Dr. Anthony Aronstam, about the prospects of me attending. He was cautious not to get my hopes up as he felt I would probably be considered too severe to qualify.

154. Dr. Hill wrote to Dr. Aronstam on 06 February and received an immediate reply on 13 February indicating that they could handle the severity of my condition, but that he should contact Mr. Macpherson the College head about the admissions process. Dr. Hill replied to confirm he would be doing that. I have letters to support this. **Exhibit WITN4607017 refs.**

155. I have since learned that the cost of supporting my attendance at Treloars was being resisted within the local authority, but Mrs. Crockett was arguing the case for me to be allowed to go. Eventually, with no other obvious alternative and the approval of all the doctors involved it was agreed that I could attend, if the College agreed.

156. My parents and I were suddenly invited to attend a day of assessment and orientation at Treloars before they broke up for the summer holiday.

157. It was a journey of nearly three hours by car to get to the lower school in Upper Froyle, near Alton, Hampshire, but we were rewarded with the sight of an impressive college set in vast, beautiful countryside. A tour of the college followed encompassing classes, boarding houses and medical facilities. We met some of the staff and saw the children with their various disabilities moving around during lessons and lunch-time. We were also guests of Mr. Macpherson at his table overlooking the lower school dining room for lunch.

158. The school was very different to Sherbourne. It had the feel of a public school with uniforms and ties, stricter rules and more of a focus on academic achievement it seemed. They even had classes (mostly leisure orientated) on Saturday morning! The day was inspiring and exciting, and by the end, despite feeling quite daunted, I was sure that's where I wanted to go.

159. In September 1979, at the age of thirteen years old, I commenced my education at Treloar's in the lower school, which housed boys under the age of fourteen years old. It was the first time I had met other haemophiliacs, I was even sharing a dorm in William Pike House with a few. Before this point there was never the opportunity in clinic and the doctors at the hospital seemed to keep us apart. It was very telling how different all of our backgrounds and severities were, despite the fact that we all had haemophilia in common. Coincidentally it would turn out to be the only time I would meet another boy with a condition as severe as mine, with inhibitors to treatment and similar historic injuries. It was the start of a lifetime bond.

160. At a time of such a new found positivity it was, and remains, hard to comprehend that this was where my life would begin its most tumultuous journey.

161. Apart from a spell of homesickness that I eventually got over, I loved Treloar's. I gained independence, confidence and social interaction not previously enjoyed.

162. The lower school had its own sick bay (medical centre), for general medical issues and bed rest if bleeds required that, with separate bays for girls and boys. The upper school had its own Sick Bay with similar arrangements. Each operated independently with their own staff. However, the Treloar Haemophilia Centre was located on the site of the upper school, initially indistinguishable from their sick bay with a doctors office and treatment room located by the entrance to the centre.

163. As there were three miles between the upper and lower schools, we would be transported to the Treloar Haemophilia Centre by one of Treloar's vans, usually they were based on the upper school. There were two daily planned runs, one in the morning after breakfast and one in the evening between classes finishing and supper-time.

164. A van would travel the 5-10 minutes to the lower school to collect anyone having a planned review or with a fresh bleed. There would usually be several boys to see the haemophilia doctor, Dr. Wassef, on the van and on arrival we would line up in the corridor outside his office and wait to be called in by him.

165. Because of my inhibitor I did not receive treatment for my bleeds, but other boys would head to a treatment room further along the same corridor to receive any Factor therapy required after seeing him. When we had all been seen and treated (if required) we would be taken back by the same van to the lower school to either re-join our classes/get supper or rest in the sick bay if ordered to do so.

166. When a new bleed occurred outside of these set times requiring immediate medical attention, we would let a member of our house staff know, then report to the medical centre where an ad hoc van would be arranged and we would be taken to see the haemophilia doctor. This was possible even through the night as the drivers and doctor usually lived on-site at the upper school and would be 'on-call' for such purposes. The arrangement meant bleeds could be assessed and treated speedily, usually within the hour.

167. When I moved to the upper school in September 1980 access to the medical centre was even easier as the entrance was just meters away from the accommodation wing and recreation room.

168. After I left college I learned the Treloar Haemophilia Centre was a part of the NHS. My parents tell me they never realised it was classed as an NHS Centre nor recall this distinction being made clear to them.

169. In terms of logistics, initially there was no separation between the upper school's general sick bay and the Treloar Haemophilia Centre. When anyone entered the medical wing, there was no sense that we were going into a different organisations premises nor a formal NHS hospital medical setting separate to the college sick bay. Instead, it felt like an extension of the college and our normal school day; the same as a planned class or break time. The only dividing line was going up the corridor to the medical wing as opposed to taking the corridor to the dining room, classes, accommodation wing or recreation rooms. It seemed like an extension of the college setting so when we were admitted for bed rest and treatment we were encouraged to bring any schoolwork to the Treloar Haemophilia Centre/school sick bay so that we did not fall too far behind. Teachers would often bring work to us if we were in for any length of time.

170. The relationship with the doctors was very different from that at my home centre. With Dr. Wassef in particular I would spend more time talking about life and our interests and in the evening he was often on site to talk to. Sometimes he and his colleague would even join the lads in the recreation room for a game of table tennis or snooker. Toward the end of my time at Treloars I even spent time exploring the viability of pursuing a career in haematology, with Dr.Wassef bringing in his notes from medical school to show me. Because the medical centre was so closely integrated with the college, the relationship didn't have the usual strict formalities you would encounter between doctors and patients, it felt much more informal and friendlier.

171. It often occurs to me now that some of the conversations we had about bleed management, treatment and physiotherapy were the type of conversations that should have taken place with our parents or legal guardian because we were still children, not withstanding the obligation regarding 'loco parentis' Treloars had, but those edges became blurred with such regular informal contact and perhaps our willingness to try new therapies was taken as adequate consent.

172. The transition from a children's NHS centre to an adult centre was also clearer outside the Treloar College setting, as I discovered when I left, but while at the college I transitioned from child to legally responsible adult without it being clear that I, not my parents, had become responsible for providing consent. Was that blurred distinction used by the doctors to justify participation in trials without parental consent, and from what age sixteen or eighteen?

173. From the start of my education at Treloar's, between 1979 and 1980, there were question marks over the treatment I received. All the haemophilia doctors at Treloar's would emphasise that my haemophilia was a very severe case, and they still could not treat me like they did other boys. I was still on bed rest, and ice packs for any bleeds or pain. It was a regular pattern. I'd just get on with it. After a bleed resolved, I would bounce back and become active again. You might lose one or two degrees movement in an elbow on the way, but that was the challenge that came with haemophilia; getting the balance right between activity, rest and active rehabilitation so that joints didn't lose their range of movement nor the muscles their strength. Despite the substantial challenges, and often getting a fresh bleed before the last one had even resolved, I felt it was never an insurmountable mountain to climb.

174. My mother was never updated about me having a fresh bleed, or being in the sick bay, neither by the housemaster or the medical centre. All her

updates came through me when I called home on the house payphone (usually having to reverse the charges which cost them a fortune!).

175. On one occasion not long after I had started there, hearing from me that I'd been in the sick bay for some time during October & November 1979 without any notification, my mother phoned the college and a message was passed to Dr. Aronstam. This prompted him to write to my mother on 19th November 1979 with a medical update and explaining why I had needed bed rest. **Exhibit WITN4607018 refs.**

176. Within four months of starting at Treloar's College (assuming the date is correct on correspondence) it is clear from my medical files that the haemophilia doctors at the medical centre were looking to test alternative approaches to my treatment, or lack of.

177. On 6 January 1980 Dr. Aronstam (Treloar's) writes to Dr. Hill (BCH) to inform him of a trial to desensitise my inhibitor through use of prophylactic Factor VIII infusions. He confirms that he has spoken with my mother about the process and benefits of the treatment but suggests it would be useful for Dr. Hill to share his opinion too. However, meeting the cost of the treatment appears to be posing a challenge and Dr. Aronstam acknowledges that the start of the desensitisation protocol will have to be delayed until funding or supply issues have been resolved. **Exhibit WITN4607019 refs.**

178. It is worth noting at this point that viral screening tests, being undertaken without my parents' knowledge, were Hepatitis B surface antigen and antibody negative and remained Hbs Ag Negative throughout my time at Treloars. However liver function screening results were markedly raised in November 1979 and January 1980 with SGOT levels of 105 and 246 (2.5 and 6 times upper limit of normal) suggestive of chronic active hepatitis. Dr. Wassef indicates in my records that he is contemplating the cause.

Autoplex (Anti Inhibitor Coagulation Complex) Clinical Trial

179. Three months after starting at Treloars, the end of treatment abstinence and the beginning of trials aimed at managing my condition using blood products was being contemplated. Two significant developments stood out. First, in January 1980, Dr. Aronstam appears to be thinking of a prophylaxis trial in an attempt to desensitise my inhibitor, this is reflected in his letter to Dr. Hill, BCH, dated 6 January 1980. Secondly, there was a development of a new activated Prothrombin Complex Concentrate product aimed at treating haemophiliacs with Factor VIII inhibitors. **Exhibit WITN4607020 refs.**

180. Finance and product supply issues were described as causing a delay to the desensitisation trial, but a trial for the new inhibitor by-passing product, Autoplex, was successfully arranged and on 16 May 1980, after a treatment break of three years, I received only my second ever course of commercial human derived Factor concentrate.

181. I had returned to Treloars after the Easter holidays on Monday 05 May 1980. My medical case notes record both my mother and myself seeing Dr. Wassef together. He notes telling us both about the benefits of Autoplex for treating my bleeds, the possibilities of a trial period and providing my mother with information to take home to discuss with my father before deciding whether to try it. He goes on to note a phone call to my mother on Friday 09 May 1980, during which she tells him she has no objections to trying Autoplex but wants to be kept informed when I am transfused. He notes reassuring her.

182. I have a vague recollection of a review with my mother present that may relate to that occasion, but possibly because of the forty-one years that have elapsed, my parents, now both around eighty-years-old, have no recollection of these events taking place at all. They have kept documents relating to my time at Treloars and diary records too, but there is no mention of these events besides taking me back to college, nor any information about AUTOPLEX, nor a copy of any signed consent form. There is an additional

handwritten note on my case notes recording an order of 12 bottles of Autoplex on 10 April 1980, almost a month before the documented discussion regarding consent.

183. I do recall Dr. Wassef talking with me while I was in the sickbay on bed-rest for a bleed about a new product they hoped could treat my bleeds without my inhibitor stopping it from working. Dr. Aronstam wanted us to try it. Dr. Wassef thought it was a good idea, and I remember being excited by the possibility of treating bleeds just like the other boys at Treloars did. Doctor Wassef suggested it may mean I had less bleeds and it might help with my attendance at school too.

184. As inhibitors were still a challenging complication of my haemophilia with no routine effective therapy available besides rest, when Dr. Wassef told me of this new experimental therapy, I was naturally hopeful and excited.

185. Doctor Wassef explained the associated risks to me in terms of not knowing how well the product would work to treat my bleeds and if it did work, whether it would be as effective as regular Factor VIII was in non-inhibitor patients. It would be a learning experience. They also needed to be sure it wouldn't cause any unpleasant side effects.

186. There was no mention of any viral, thrombotic or long-term risks that I have since learned were well known considerations at that time, and I never saw any product packaging or information sheets as the material was always mixed by the medical staff.

187. As I was only fourteen years old at the time, I'm sure I would have said to the doctors that they would need to speak to my parents about starting on any new treatment. With hindsight I would also have expected the opinion of my consultant, Dr. Hill, at my home centre to be sought as he had been an advocate of treatment abstinence in case I needed it in the future for a life-threatening bleed.

188. Thereafter, I was told a telephone conversation with my parents had taken place and we had approval to try the new product. I understood that it was Dr. Wassef that had spoken with my mother.

189. On Friday 16 May 1980 I woke up with a fresh left knee bleed and immediately reported to the sick bay. The infusion of Autoplex or "*anti inhibitor coagulant complex*" was prepared by Dr. Wassef and administered by intravenous infusion in much the same way as Factor VIII but with larger volumes involved in reconstitution and administered much more slowly. I have details of these treatments if required.

190. He reassured me that because the product was brand new that extra precautions would be taken in case it caused any reaction. Instead of being in the regular treatment room sat at a table like the other boys this meant I was instead prepped in a side treatment room lying on a bed with the various doctors and nursing staff around me.

191. In the room at the time of the treatment I remember Dr. Wassef and another doctor being present, one on either side of the bed with my arms outstretched for them to access, and a senior nurse standing at the foot of the bed recording observations. Dr. Wassef was administering the treatment whilst the other doctor was continually monitoring me and making sure that I was okay. Nearby, apparently, was a 'crash trolley' that the two doctors made sure I had knowledge of in case of "*emergencies*." They also took copious blood samples, pre-infusion, during and at regular intervals post-infusion and were constantly monitoring my pulse, blood pressure and physical reactions. I had to give a verbal commentary on how I was feeling throughout.

192. At first, the Autoplex was administered with great caution and at a very slow rate. I was told that this treatment was brand new, and that it had not been used before, therefore, it had caution attached, as there was a potential for an adverse reaction. To reduce the risk I was also administered a dose of Piriton before the infusion started.

193. Over the course of what seemed like hours but in reality varied between 30 minutes and an hour for each infusion, depending on how many reactions I experienced, the doctors very carefully treated me. Overall it would take around two hours to complete the trial infusion including preparations, the very slow, start-stop-start infusion, and any necessary trial blood tests and observations.

194. I felt every drop of the infusion from the very first tentative push on the syringe. It had to be stopped frequently because of my body's reactions. Some of the reactions I complained of were a tight chest, head-rush, a pounding heart and abdominal pain. Other times I became flushed, faint, dizzy and felt like all my blood was rushing to my head at once. My blood pressure would sometimes fluctuate and I'd experience palpitations.

195. Despite the excitement of this potentially new treatment, it was frightening at the same time as I was still a child, but Dr. Wassef did instil great confidence in his skill as a doctor, and I felt as though I was a bit like a maverick, breaking new grounds for haemophiliacs in the future by trialling the new drug. After the treatment finished, I always felt very tired and spent the afternoon sleeping off the side effects.

196. Thereafter, Dr Wassef would monitor the speed I would get over bleeds and report back to Dr. Aronstam. After the first and second use, the Autoplex had lessened my bleeding episodes. The results were promising and it felt like a step in the right direction of controlling my bleeds.

197. Autoplex was not the easiest to prepare and the frequent reactions during infusion plus the greater numbers of medical staff required for monitoring did not make this the most convenient product to use. Cryoprecipitate, described now by some clinicians to be inconvenient, seemed by comparison far less problematic to me, although admittedly would not be very effective with a high titre inhibitor present.

198. I received Autoplex for one further bleed in June 1980 while I was attending Treloar's lower school. After the summer holidays, in September 1980, I moved to the upper school of Treloar's at Holybourne, residing in Gauvain House, which made access to the haemophilia centre much easier as the entrance to it was just a few rooms away at the end of my dormitory corridor.

199. The doctors at Treloars used Autoplex for a number of my severest bleeds during my attendance right up until June 1984. Not all bleeds were treated; only my severest bleeds received Autoplex, or later other products, with many going untreated, besides rest and pain relief.

200. My parents were told very limited information about the treatment I received, or even when I was in the sickbay. Neither of us recalls being told of the associated risks of this new blood product, such as thrombosis or viral dangers. I learnt about this later as an adult. Any news about my health, or information about the treatment received, was mostly left up to me to deliver during phone calls home or was sometimes summarised in my end of term school report that contained pages for physiotherapy and medical updates. I have a selection of these if needed by the IBI.

201. I have since been reminded of a clinical trial after reviewing a number of documents, which have been brought to my attention by the IBI Investigators. These highlight that in addition to the 1980 clinical trial, I later took part in a revised Autoplex Clinical Trial in 1983, under the care of Dr. Aronstam & Dr Wassef. The trial compared the efficacy of Autoplex against the use of Factor VIII.

202. Dr. Aronstam wrote to my parents on 02 May 1983 to seek their approval for my participation in a clinical trial, initiated by the Haemophilia Centre Directors of Great Britain, with the purpose of identifying which treatment, Factor VIII or Autoplex, was the best treatment for people with inhibitors.

203. There is no signed consent form in my medical records, but I possess a letter with a hand written note by my mother that confirms my parents were

informed and in agreement with my participation. It appears to show her intention to provide consent but a copy of the letter is not contained on my medical records so I am unclear if formal consent was provided. It would appear consent must have been given, at least informally, and subject to my agreement too, as it was noted in my end of term medical report.

204. My participation in an Autoplex Clinical Trial at Treloar's in 1983 is confirmed within a letter dated 19 May 1983, from A Cameron, Senior Scientific Officer, Travenol Laboratories Limited, to Dr A Aronstam, Director of Treloar Haemophilia Centre, entitled 'Autoplex Clinical Trial.' The letter outlines my respective patient identification numbers, and that the material was supplied by Travenol Laboratories Limited. This letter; with a URN of **HHFT0001159_001**, is exhibited as **WITN4607002.**

205. This trial was outlined in the Trial Protocol, dated 01 March 1983, entitled 'Clinical Evaluation of AutoplexR (Anti Inhibitor Coagulant Complex) in Inhibitor Patients,' as being a 'double-blind single cross over study.' This is where participants receive either real treatment being studied or placebo (in this case the standard clotting product Factor VIII being compared) for a time, and then are switched ("crossed over") to the opposite treatment, so that each person gets both standard and new treatment. This Trial Protocol; with a URN of **HHFT0001159_003,** is exhibited as **WITN4607003.**

206. Instruction for the Autoplex Clinical Trial is contained within a flowchart, undated, entitled 'Autoplex Clinical Trial: Instruction Flow Chart for Autoplex V Factor VIII Trial.' This document has a URN of **HHFT0001159_002**, and is exhibited as **WITN4607004.**

207. I was listed as 'Patient 3,' with a trial number of '33' in handwritten notes, dated September 1983, entitled 'Autoplex Clinical Trial (Autoplex V F VIII Trial).' This note also details the other patients selected for the trial, and that my current alternate day prophylactic treatment 'Factorate' should be stopped for 24 hours during the trial dosing period. This document with a URN of **HHFT0001157**, is exhibited as **WITN4607005.**

Inexplicable use of Hemofil Factor VIII

208. On 11 January 1981 my medical records show in my term case notes that there is a single use of 3052 units of Hemofil Factor VIII, but there are no corresponding treatment records on file. Considering my previous treatment abstinence to avoid stimulating my high responding antibody that would render such use of limited value, to suddenly use this product in this way seems a strange decision. I find this perplexing as to its purpose given the associated viral risks. Was it some form or experiment too? **Exhibit WITN4607021 refs.**

Porcine Factor VIII Trial

209. On 12 January 1981 there is an indication on my Treloar medical records that I was included in a further study, this time trialing the use of Porcine Factor VIII. There are no details of the nature of the studies, protocol or aims on my file. A brief note is recorded of Porcine use on 12 & 13 January 1981 and again on 01 March 1982, and listed at various points in my termly treatment summary records. There are various corresponding formal laboratory tests but the detailed bleed record sheets are missing from the file and it is therefore neither possible to identify what the clinical indications for use might have been, nor whether its use resulted in any clinical benefit. Again I have copies of these records if required. **Exhibit WITN4607022 refs.**

210. Neither my parents nor myself have any recollection of a request to use Porcine for the treatment of non-life-threatening bleeds by the doctors at Treloars. There is no indication on file of consent being sought or given, formally or informally.

211. The result of this study is stimulation of my Porcine inhibitor which becomes highly elevated for a prolonged period of time (at least 6 months). This

renders the product ineffective for further bleed management and in particular excludes its potential use in the treatment of a life-threatening bleed should one arise.

212. The use of Porcine Factor VIII is also contrary to the indicated preference of my home Haemophilia Centre, as indicated in a letter of introduction from Dr.Hill, BCH, to Dr. Aronstam, Treloars, dated 6 February 1979, in which he indicated a policy of treatment abstinence to allow inhibitor levels to fall, thus preserving Factor VIII containing products for use in a life-threatening situation.

213. With previous experience showing my Porcine inhibitor would produce a very high titer (concentration of specific antibodies) if stimulated, any benefit derived from its use was certain to be extremely short lived. I find it perplexing why this salvage therapy would have been used in such a way for a routine bleed, or just to satisfy a study.

FEIBA (Factor Eight Inhibitor Bypassing Activity) Clinical Trial

214. On 08 December 1981 and thereafter throughout 1982, I was given my second commercial human derived activated Prothrombin Complex Concentrate product, "FEIBA" (Factor Eight Inhibitor By-passing Activity). **Exhibit WITN4607023 refs.**

215. FEIBA was used as treatment for some severe bleeds and, at least initially, was given as carefully as Autoplex with similar precautions. As time went on and it became clear that I didn't experience the same number of adverse reactions during infusion the precautions were relaxed. Because it was mostly used for severe bleeds I was in any case often admitted to the sick bay for rest, observation and pain relief.

216. Although very similar to Autoplex, FEIBA thus proved easier to administer. However, the product still continued to have the disadvantage of requiring large volumes of reconstituted product that required slower infusion,

compared to Factor VIII concentrates, and remained less effective with bleeds still taking longer than average to heal and remobilise.

217. Like the trial of Autoplex, there were no other significant risks described with its use beyond the uncertainty of how effective it would be. I discovered later that the risks were essentially the same as for Autoplex; Thrombotic events and viral infections with potential long-term consequences. Because doctors always prepared and infused the material I never saw any product packaging or accompanying information.

218. Dr. Wassef told me that I would be one of the first to receive FEIBA and the hope was that it would be as effective as Autoplex but easier to administer and that I'd find it a better treatment, with less side effects. I recall him mentioning that I would be receiving it as a named patient, but at that time I had no understanding of the significance of that terminology.

219. I remember talking about FEIBA and agreeing to try the treatment to see if it was better than AUTOPLEX. The same excitement at being involved in ground-breaking developments was once again present, but I have no recollection about the opinion and consent of my parents or home consultant being sought this time and have often wondered whether this might have been because I was now 16 years old and this made some difference to my designation as a child; if it did I was never told.

220. With very few treatments available for the treatment of haemophilia with Factor VIII inhibitors, FEIBA ultimately became a product of choice by the doctors at Treloar's and later by my home treatment centre too, being used regularly right up until 2019.

221. I have since come to learn that Baxter have had interests in both FEIBA and Autoplex. At the time of my first infusion with these inhibitor by-passing products, Autoplex was manufactured by Baxter's Hyland Therapeutics Division, Travenol Laboratories, and FEIBA by the Swiss company Immuno International AG. In 1996 Baxter International acquired Immuno International

AG and with it the rights to FEIBA. As part of the acquisition Baxter consented to divest its Autoplex product to meet American FTC competition requirements. I recall hearing that both of these products were administered on a named patient basis but at that time did not understand what that meant.

222. Both products were an improvement for the treatment of my bleeds and although imperfect offered hope that new more effective treatments were being developed.

223. As a child I had no understanding of the manufacturing process of blood products and this was never explained to me by anyone. My parents grew up in an era where you did not question doctors and so put total trust in their judgement as physicians without being fully informed.

224. Much later, as an adult investigating how I came to be infected with HIV, my research provided greater understanding and raised with it the question of why these large-pooled blood products, made from paid-for American blood sources of dubious quality, were considered safe and given approval for use in the UK where the risks were well established and, at least for cryoprecipitate or Factor concentrates, small-pool British donated blood products from carefully screened (non-prison) donors could have proven a safer option?

225. My parents continued to receive very limited background information about FEIBA and Autoplex There was not any mention of potential life-threatening viral infections. Information about when I received treatment with one of these products was still provided to them by myself not the doctors, there were no communications to discuss options or seek consent. Dr Aronstam and Dr Wassef were looking at and weighing the risks vs benefits and it appears to me they were focussed on the physical effects of the treatment, and not, at the future risks associated.

226. Looking back over the on-demand use of Cryoprecipitate, whole blood, Porcine and activated prothrombin complex concentrates (Inhibitor By-passing products) it is notable how infection risks rose dramatically with commercial concentrates.

227. It is clear to see that my substantial use of Cryoprecipitate and Whole blood did not result in any viral infection up to 1971, but my first exposure to human Factor VIII concentrates in June 1977, resulted in symptoms probably indicating an episode of hepatitis around 28 days after infusion and then, after further treatment abstinence, apart from a single inexplicable dose of Hemofil on 11 January 1981, between May 1980 and February 1983 the inhibitor bypassing concentrates were the only human derived blood products I received at Treloar's, all used for non life-threatening bleeds, and must therefore have been the route of my infection with HIV.

228. A HIV positive test was confirmed in a retrospective test on a frozen blood sample taken in January 1983, although this was not known until requested by my lawyers Newsome Vaughan & Co on 9 November 1988. (They represented me regarding the legal action into my infection with HIV)

Bonn Protocol

Exhibit WITN4607019 refs.

229. On Monday 31 January 1983, I woke up with a particularly severe right elbow joint bleed. It rapidly developed to became extremely stiff and painful. Despite immobilisation in a plaster cast, an initial transfusion with Autoplex and an evening follow-up dose of FEIBA, by 4.30am the next morning the bleed had worsened. I received a further two doses of FEIBA without signs that the bleed was resolving. At this point Dr. Wassef, having consulted Dr. Aronstam, took the decision to infuse me with two massive doses of human derived Factor VIII the first on the evening of 01 February and another the following morning. By Thursday 03 February there were signs of improvement, but full recovery would take around a further month to achieve.

230. During my years of treatment abstinence I would have just had to wait for such a bleed to resolve, even one as severe and painful as this. Life would stop and I would have a week or more of bed-rest, ice packs, sleepless nights and barely effective strong pain relief. It was horrible, traumatic and no doubt distressing for others to witness, but I did get through it safely and still managed to bounce back afterward. It was not life threatening, and not usually life-altering in the longer term.

231. On this occasion, with recovery established, before being discharged from sickbay the following weekend, Dr Wassef had a conversation with me about my treatment. He proceeded to tell me that Dr Aronstam and himself were starting me on prophylactic Factor VIII, like an experiment called the Bonn Protocol that had managed to get rid of the inhibitor in haemophiliacs like me. He said I would be the perfect candidate to take part in the trial and it could result in a real improvement to how they treated my bleeds in future and may even assist with being able to perform surgery to help my left knee.

232. The Bonn protocol was developed in Bonn, Germany in the late 1970s. It was an immune tolerance inducing protocol developed by Dr Hans-Hermann Brackmann. It involves regular administration of Factor VIII replacement therapy in conjunction with activated prothrombin complex concentrate (FEIBA) over a prolonged period of time. The purpose is to stimulate the inhibitory antibody that is seen to rise to a high level before eventually peaking and gradually dropping to a low level. The target outcome is for eradication of the antibody or to lower it to such an extent that routine on-demand treatment with factor replacement, or lower levels of prophylaxis become viable.

233. I wasn't told what the Bonn Protocol entailed at the time of the trial beside prophylactic Factor VIII, but I learnt more about it years later, and in so doing discovered that my prophylaxis trial excluded the prophylactic FEIBA aspect, so that this wasn't a pure Bonn Protocol, but instead a new variation being explored.

234. The aim of the trial proposed would determine whether by treating me with high levels of High Purity Factor VIII (Factorate) alone on a regular basis over an extended period, it would desensitise and possibly remove my Factor VIII inhibitors. Although the trial ultimately failed for me, possibly because my inhibitor was of long standing nature, the approach became established because of its success in a large proportion of cases.

235. Currently, immune tolerance inducing therapy remains the only proven clinical method for removing Factor VIII inhibitors but research continues to help understand the full mechanism involved and why it fails in certain cases. After inception, a number of protocol variations were explored at various centres internationally until in 2007 an International Workshop of leading clinicians produced consensus recommendations on best practice.

236. After talking with Dr. Wassef, aged 17, I agreed to take part as I trusted Dr Wassef and Dr Aronstam, and I thought that it was a good idea, if possible, to get rid of my inhibitor as it would have a beneficial effect on managing or even reducing my bleeds, plus it appeared to make the prospect of surgery on my left knee a viable proposition. I was basing my decision on the benefits of replacement factor that was described as safe. I had no knowledge of any other risk factors that might have informed my decision more fully. My mother has no recollection of being contacted by any of the Treloars doctors at that time and believes she only heard about the start of the protocol from myself.

237. After obtaining my medical records in the 1980's as part of the HIV litigation, I retrospectively became aware that Dr. Aronstam was planning to carry out the protocol as early as 1980. Dr Aronstam wrote to Dr Hill around November or December 1980. Dr Hill responded on 4 December 1980. Again I have copies of these letters if required. This came to my knowledge due to a letter dated 4 December 1980 from Dr F G H Hill, Consultant Haematologist, Birmingham Children's Hospital, to Dr A Aronstam, Consultant Haematologist, Treloar Haemophilia Centre, Lord Mayor Treloar College in response to his proposal, and also a letter, possibly mis-dated as

6 January 1980 (instead of 1981), from Dr. Aronstam to Dr. Hill describing the problems of treatment supply for a desensitisation process.

238. In his letter of 4 December 1980, Dr. F G H Hill comments that the only reason they had managed to treat my previous life-threatening bleeds was by withholding Factor VIII to allow my inhibitor to fall to a level that allowed treatment. He went on to say that the results of the 'Bonn' regime looked impressive and would be worthwhile attempting. Dr.Hill describes the possible benefits as outweighing the 'immediate risks', though which risks he had in mind are not clear. Was he referring to the risk of ITT failure with a resulting high titre inhibitor, or perhaps infection with known viral risks? Dr. Hill also added that he did not think he could help with financing the process out of his current budget.

239. This early exchange of letters on the matter also capture Dr. Aronstam reportedly having a telephone conversation with my mother to explain the desensitisation process but suggesting she would benefit from a further chat with Dr.Hill who, in his letter to Dr. Aronstam on 1 December 1980 is keen to establish whether my mother has been spoken to and offers to see her in his clinic. There is no further correspondence to confirm what further conversations, if any, took place nor, perhaps more importantly, whether she provided any form of consent to proceed. My mother tells me she has no recollection of discussing the matter with any of the doctors, but would have supported whatever my choice was.

240. After the initial proposals in 1980, the difficulties of treatment supply and finance appear to have delayed starting the trial until events unfolded on 11 May 1982. Dr. Aronstam writes to Dr. Hill informing him of a visit by Travenol's men and an offer to donate 25% of the Factorate required or alternatively cut their bill by 25%. He mentions that Dr. Geoff Savidge, haemophilia consultant, St. Thomas' Hospital, London, also has knowledge of the planned protocol and is offering £50,000 toward the cost. On this newly established basis he states his intention to apply for further funding from the regional budget.

241. On 20 May 1982, Dr. Hill confirms that Birmingham Children's Hospital did not think that they could support my treatment for Factor VIII, due to a 30% rise in their own Factor VIII expenditure. This letter has a URN of **TREL0000335_031**. (Exhibited below, as **WITN4607006)** in it he also states:

"I am delighted to hear that you have twisted the Travenol men's arm that they will donate 25% of the Factor VIII needed for an immune tolerance protocol."

242. After a further 10-month delay the supply and financing constraints had been resolved and on 03 February 1983 I started treatment under the protocol.

243. Thereafter I was trained by the medical centre haemophilia nurses how to mix the Factorate and to self-infuse. A few months later I was given a supervised test that I passed. This confirmed my proficiency and I was allowed to self-infuse without supervision from that point onward.

244. As part of learning to self-infuse I was given a training manual that covered a number of subjects ranging from what haemophilia is and the genetics involved through to how to reconstitute the Factor concentrate and infuse safely. I still have this manual and produce a copy as **Exhibit WITN4607024 refs.**

245. Near the end of the manual there is a single sheet entitled "Hepatitis". It describes hepatitis as a virus that results in jaundice that can progress to chronic hepatitis, although it does not enlighten the reader as to what this outcome would mean in clinical or personal terms. The text goes on to explain precautions that should be taken to protect others such as cleaning blood spillages with bleach and sheathing and disposing of used needles safely.

246. There is a warning that any blood product carries a risk of hepatitis but this risk appears not to be of great concern to haemophiliacs as it says:

"Haemophiliacs have a high resistance probably developed as a result of repeated blood transfusions this being shown by the presence of an antibody in the blood."

There follows a reassurance:

"although many have the antibody, very few have had severe jaundice."

247. It appears then, as mentioned to me dismissively in 1977 by Dr.Rizza, that hepatitis was nothing to worry about, you may get jaundice but you get over it. There is no hint of it being a serious life altering or life limiting condition.

248. Throughout the protocol, I received regular treatment of Armour Factorate.

249. This is confirmed within a letter dated 24th March 1983, from Dr M Wassef, Senior Clinical Medical Officer, Treloar Haemophilia Centre, Lord Mayor Treloar College, Basingstoke and North Hampshire Health Authority, to Dr. F. G. H. Hill, Birmingham Childrens Hospital, in which he confirms that Joseph started his tolerance inducing protocol on 3.2.83 and was receiving approximately 900 units Factorate on alternate days until 19.2.83 and thereafter on Mondays, Wednesdays and Fridays.

250. The letter includes inhibitor tests that show the expected ITT pattern, rising, peaking and apparently beginning to decline. The protocol was started when my inhibitor was 93 New Oxford Units. This would now be considered a predictor of failure with success achieved when the inhibitor is less than 10 Bethesda units at the start of the protocol.

251. The continued use of Armour Factorate is further confirmed within a letter dated 27 March 1984, from Dr M Wassef, Senior Clinical Medical Officer, Treloar Haemophilia Centre, Lord Mayor Treloar College, Basingstoke and North Hampshire Health Authority, to Dr Strevens, Coventry and Warwickshire Hospital. During my Easter holidays in 1984, I was transfused

with 990 units of Armour Factorate on alternate days. My treatment required seven doses starting on Monday 15 April 1984. This letter has a URN of **TREL0000335_012**, and is exhibited as **WITN4607007.**

252. This is further confirmed in a letter, dated 06 April 1984, from Dr M Wassef, Senior Clinical Medical Officer, Treloar Haemophilia Centre, to Dr Strevens, Coventry and Warwickshire Hospital. Dr Wassef thanks Dr Strevens for providing me with Armour Factorate for my tolerance inducing protocol during the Easter Holiday in 1984. This letter has a URN of **TREL0000335_011**, and is exhibited as **WITN4607008.**

253. Between February 1983 and June 1984, the protocol was having an effect on my inhibitor levels. However, as illustrated in a graph, undated, whilst the Factorate treatment received had an initial effect on my inhibitor levels, it slowly declined to the inhibitor levels that had previously been recorded before starting the protocol. These results had shown that the Bonn-style protocol was unsuccessful. This graph has a URN of **TREL0000335_085**, and is exhibited as **WITN4607009.**

254. Within a letter, dated 07 June 1984, from Dr M Wassef, Senior Clinical Medical Officer, Treloar Haemophilia Centre, Lord Mayor Treloar College, Basingstoke and North Hampshire Health Authority, to Dr M Strevens, Coventry and Warwickshire Hospital, Dr Wassef informs Dr Strevens about the rise in my inhibitor level. They also discuss plans for my future treatment once I left Treloar's. This letter has a URN of **TREL0000335_015**, and is exhibited as **WITN4607010.**

255. I posses a letter from Dr. Strevens to Dr. Wassef dated 25 June 1984 in which Dr. Strevens indicates that he feels the protocol should be abandoned and use of FEIBA would be the most appropriate future treatment.

256. The doctors at Treloars complied with his instruction and stopped my treatment under the Bonn-style Protocol on 27 June 1984.

257. This is confirmed within a letter, dated 10 July 1984, from Dr M Wassef, Senior Clinical Medical Officer, Treloar Haemophilia Centre, Lord Mayor Treloar College, Basingstoke and North Hampshire Health Authority, to Dr Strevens, Coventry & Warwickshire Hospital.

258. The letter outlines that my tolerance inducing protocol was stopped on 27 June 1984. My inhibitor levels on 19 June 1984 persisted at 53 units (New Oxford Units). This letter has a URN of **TREL0000335_109,** and is exhibited as **WITN4607011.**

259. The failure to eradicate my inhibitor was a great disappointment at the time. However, with the knowledge I have gained since about the known risks of hepatitis viruses in blood products at that time and the potential vector to carry other viruses because they had not been adequately protected from contamination, and for which no viral inactivation process had been employed, I find it astonishing that such a high exposure, high risk protocol was embarked upon at that point in time for an experiment.

260. From December 1980, when Dr.Hill agreed with Treloars doctors that immune tolerance would 'outweigh the immediate risks', until February 1983 when the experiment began, a period of over two years, the state of knowledge about hepatitis and the unfolding dangers of AIDS had progressed significantly. Shouldn't a reassessment of the 'immediate risks' have been made in 1983 that should have indicated avoidance of my unnecessary exposure to potentially high viral titre commercial concentrates that would potentially infect and go on compounding the viral load with repeated exposure of further viral load and virus variants?

261. It may ultimately have proven too late to prevent my exposure to hepatitis viruses, and HIV by February 1983 when the Bonn-style protocol began, but the doctors did not know that for certain and should have been limiting my exposure to commercial blood products at that time.

262. It would also seem highly dubious that a product manufacturer or the department of health would approve the use of such potentially dangerous products at that time for anything other than intervention of last resort in a life threatening situation.

Factor IX Trial Exhibit WITN4607025 refs.

263. In October 1983, aged 17, my medical records show another experiment was undertaken by Dr. Aronstam, LMT Haemophilia Centre, in co-ordination with Dr.T.J.Snape, Head of Quality Control, Blood Products Laboratory. Factor 9 was used on a 'Named Patient Basis'. The purpose of the trial was to evaluate clinically "the use of Factor IX concentrate in Haemophilia A complicated by inhibitors to Factor VIII". It appears from the records that Factor IX was trialled with and without an additional agent (illegible).

264. My medical records show that I received nine infusions of BPL Factor IX concentrate between 18 October 1983 and 28 March 1984. There are record sheets available for all but the first two infusions.

265. Although my end of term medical report to Dr. Hill at BCH by Dr.Wassef of LMT Haemophilia Centre notes the use of Factor IX, it also describes a reasonable clinical response as the outcome, this appears at odds with a review of the report sheets that show a clinical response was only seen in two out of seven infusions to treat active bleeds. The remaining five available had 'no clinical response' recorded next to them.

266. There is, yet again, an absence of documentation indicative of parental consent, or even my informal consent, albeit I had not yet reached eighteen years of age and should not have been providing consent without parental knowledge.

267. My mother cannot recall receiving a request to treat me using Factor IX by the doctors. Neither can I. The time frame, with suspicions about

transmission of AIDS via blood products being very prevalent within the scientific and medical community, would appear to make this trial an extremely risky, unnecessary experiment to perform on me at that time. If provided with all available facts at that time I believe I would not have provided my consent to this trial.

Other Infections - Earliest Viral Awareness & HIV Diagnosis. Exhibit WITN4607026 refs.

268. Shortly after beginning treatment under the Bonn-style protocol, I had started to form a romantic relationship with a girl from GRO-C Hampshire, who I met at a Treloar's social event. My relationship lasted from March 1983 to January 1984, which was GRO-C after my eighteenth birthday. At this point, there was no hint of me needing to be careful about viruses or protecting a partner.

269. To the best of my recollection, apart from the information sheet in the self treatment training manual which informed me haemophiliacs were highly resistant to hepatitis, my first knowledge of there being any sort of real hazard with the medication being used to treat my bleeds was a short while after this relationship, during the spring term of 1984. I was told to report to Dr. Wassef in the new medical centre after completing my classes. The precise date and details of the consultation are absent from my Treloar medical records. I find this odd considering the monumental significance of the occasion and the coordination required with the college.

270. I was now aged eighteen-years-old and due to leave Treloars/Alton 6th Form in the summer after my final 'A' level examinations. When I reported to the new medical centre it became apparent that Dr Wassef was calling batches of haemophiliac boys into the doctor's office each in turn. I enquired what it was about with one of the boys that had already been seen and was

informed they were told not to say anything to anyone else about what was said.

271. When it came to my turn to attend the doctor's office, I was asked to take a place alongside a group of other lads from my year group and the year group below. Most of the lads were standing in the office and Dr Wassef stood by the door addressing us all.

272. Dr Wassef proceeded to state something along the lines of "*you may have heard that something is going on in America, it looks like there's a bug in the blood and it could affect the treatment you are all receiving. We do not know what is going on or what it means for you yet, but we need to get you all to do some blood tests for us to check.*"

273. One of the lads in the doctor's office proceeded to ask Dr Wassef if he was talking about AIDS, to which, he replied that there was thought to be a bug in America that caused AIDS and that could be transmitted by blood. Therefore, as the Factor VIII we were receiving as treatment for our haemophilia was made from American blood, it looks like we are at risk of getting the bug too.

274. When I was a student at Treloar's it felt like I was in a secluded bubble. We rarely heard anything about what was happening in the outside world, as we were very sheltered when it came to news. National news on television usually coincided with lessons in the day, dining time in the evening or after the 'lights out' time at night. Newspapers were not readily available. Despite this, there had been a growing awareness of AIDS among some of the boys, probably from media coverage during the holidays, but most of the lads had no real idea what Dr Wassef was talking about and none of us imagined it would relate to us in any way.

275. This was devastating news to us. Whenever we were treated with Factor VIII, or any of the other concentrates, we did not see the labels on the bottles fully, and if there was any glimpse, we did not see any information on the

bottle about any associated risks. As children you trust that the medication you are being given by the doctor is safe.

276. Even as children we were encouraged to check the expiry date and batch number, which had to be recorded, but our attention was never drawn to any infection warnings.

277. Dr Wassef proceeded to tell me and the other lads to go to the Treloar Haemophilia Centre, treatment room, which was still located in the original sickbay, where a number of blood samples would be taken. When we arrived, the room was full of lads having to give blood.

278. When the blood was taken, we were surprised just how much was drawn up and with such large needles. Normally, because I take a long time to stop bleeding, a small twenty-three gauge needle would be used, but this time it was a nineteen gauge, two sizes larger. It enabled the large quantity of blood to be taken quicker but it meant I would bleed for a lot longer once it was withdrawn. In fact the nurse was a little concerned when I went back the next morning with the cotton wool still taped on my arm because I hadn't stopped bleeding!

279. The substantial amounts of blood taken equated to several 50ml syringes in total. The nurse told me that they were taking so much blood from us because of all the tests that needed to be done. I have since discovered it was also to allow them to freeze some of it for future testing if it was needed. There was no suggestion that giving the blood was a choice that could be refused.

280. That evening, after I had returned from giving blood, I phoned to tell my mother about what I had been told with regards to the dangers associated with the blood product I had received as treatment for my haemophilia and about the blood taken. She was really concerned as this was the first time she had heard of any concerns about my treatment. I discovered then that my parents had received no communication from the doctors, my

housemaster or anyone from the college about the doctors concerns or that I was going to receive such distressing news. There was no emotional support arranged for either of us. For something so life altering, it was treated very casually.

281. Since I received my first commercial concentrate at Treloars in May 1980 there had been a number of occasions when I had experienced severe flu-like illness for unusually extended periods. I had also experienced increasing fatigue and lethargy with clouded thinking and uncharacteristic problems with my memory. I also recall a time when I had a swollen tummy and unusually dark urine, reminiscent of the occasion when I got hepatitis-like symptoms after being treated in Oxford, but because I was also having bouts of haematuria I thought that may be the cause.

282. At the end of 1983 I had again been experiencing flu-like symptoms. This time they lasted over three months. A noticeable change in my health had occurred. I was now suffering with prolonged symptoms. The fatigue wiped me out and after attending classes I would need to sleep throughout the evening and night but never felt refreshed. I couldn't concentrate and my memory seemed impaired. My mood plummeted, particularly after I received the news Dr. Wassef revealed to us all. My studies and ultimately my 'A' level finals were inevitably impacted. My mother had become concerned, and raised this with Dr Wassef and Dr Aronstam. The reply that she received from Dr.Wassef about her concerns on that occasion was that I was simply experiencing a bad cold.

283. With hindsight, I now associate those repeated flu-like occasions with probable HIV infection and sero-conversion, and the extreme lethargy and dark urine with repeated Hepatitis B infection (despite blood screening being applied for hepatitis A & B since around 1974). The LMT & Coventry records I have show I became HBV surface and core antibody positive in December 1983 tests.

284. With the media coverage intensifying, my repeated flu-like episodes and now my phone call relaying Dr.Wassef's news, my mother grew extremely concerned. She was confused because she trusted that if there was anything to worry about then the doctors or college would surely have contacted her. They didn't. Ever.

285. A short while later, during one of my evening calls home, my mother told me she was so worried that she had phoned Dr.Wassef to express her concerns about the safety of my treatment particularly in light of reports she had heard on the news about the prevalence of AIDS in America. Also, about its association with haemophiliacs.

286. My mother knew that I was being given American Factor VIII for the tolerance trial, so due to the concerns over the safety of the blood products, she had asked for me to be treated with a British blood product instead. Dr Wassef had immediately reassured my mother that the blood products were fine, that the one I was on was safe and was nothing to be concerned about.

287. I have retrospectively become aware by inspecting some of my medical records that my mother's telephone conversation of January 1984, in which she expressed her concerns over the American factor concentrate safety, had been written down. Noted in Dr Wassef's handwriting was a description of her concern about AIDS and her request to change me to a British product. After the note is the word "*reassured.*" The note is signed by Dr. Wassef and dated 25 January 1984.

288. Confusingly, I also retrospectively discovered that Dr.Wassef and Dr.Aronstam were testing me for 'AIDS STIGMATA' around the same time my mother was receiving reassurance, and possibly at the time the large amount of blood was taken.

289. My mother and myself find these events bewildering. They have left me deeply conflicted. Why had Dr Wassef, a doctor who had gained my trust and respect, reassured my mother about the safety of the treatment I was

receiving? All the while, he knew there were issues. The doctors were undertaking AIDS surveillance tests and had expressed that there was something to be concerned about to the haemophiliacs attending Treloars. Even if he somehow had not known for certain about the real risk of blood borne virus associated with American Factor VIII in January 1984, which given the knowledge among UK Haemophilia Centre Directors I find highly unlikely, and instead, gained knowledge in the period leading up to July 1984 when I left Treloars, he should have notified my mother about his newly gained knowledge, but my parents never received any communication from the doctors or the college about the risk from the treatment I had been given and any information they communicated to my home centre was not passed on to me. There doesn't seem to be any justification for 'reassurance'.

290. Subsequently, in light of this information, this raises questions over whether Dr Wassef and Dr Aronstam had been truthful about the safety of the trial, and when my mother raised questions about the state of my health in the period of 1983 and 1984 when the Bonn-style trial was proposed and I received treatment under the tolerance protocol.

291. Between 1983 and 1984 when I was being treated under the Bonn-style protocol, I received in excess of 220,000 units of Factorate over the period of the trial, a substantial exposure to American commercial Factor VIII that was unnecessary at that time. It wasn't needed for any clinical reason beyond the trial. This was sourced from multiple batches of Armour product.

292. During the spring term 1984 I had also began to form a romantic relationship with a girl who was a student at Treloars.

293. However, when the staff at Treloar's college learned about my romantic relationship, they were very against me seeing her or having any contact. It was not until later when I connected the events described above that I would realise the reasons why the staff at Treloar's were intent on discouraging me forming a potentially intimate relationship.

294. To me, this shows there was awareness among the college staff about the infections I and other haemophiliacs were affected by. It also shows concern about potential sexual transmission, although no one had warned me that was a risk or what to do about it to protect any potential partner.

295. Curiously, after stopping the Bonn protocol in June 1984 the flu-like symptoms improved and, on 07 July 1984, at the age of eighteen I left my education at Treloar's, newly burdened with a life-changing uncertainty.

296. Around four years after leaving Treloar's, a number of points relating to the events described above were revealed to me.

297. With the news that I was infected with HIV, and was likely to face a very premature death as a result, I had sought legal advice. At the outset of my exploration of legal action into my infection with HIV as a result of the multitude of blood products unnecessarily administered to me during the period of greatest risk, my solicitor sought and obtained my LMT medical records that I then had the opportunity to review. I have correspondence from my solicitors showing the request for my medical information dated 9 November 1988.

298. My medical records revealed several facts unbeknownst to me at the time. Doctors at LMT had been testing me for signs of infection with hepatitis from the moment I began attending LMTC in 1979 and had noted 'intermittent but markedly raised SGOT liver function tests'. Raised Alkaline Phosphatase, which I understand can possibly indicate the existence of liver damage occurring, is also noted.

299. Furthermore, there is evidence of tests being performed in relation to AIDS that are summarised on a sheet entitled 'AIDS' and dated 14 February 1983. Hand written 'Spring Term' review notes dated 14 June 1983 go on to describe the basis of on-going suspicions that I was exhibiting signs of AIDS.

300. I discovered the concerns of Dr. Aronstam and Doctor Wassef of the LMT, Haemophilia Centre and results of their 'AIDS related investigations' into 'Stigmata of AIDS' were communicated to Dr. F. Hill of BCH and copied to Dr. Strevens, of Coventry Haemophilia Centre. However, none of this was communicated to my parents or me.

301. This is confirmed within a letter, dated 29 June 1983, from Dr M Wassef, Senior Clinical Medical Officer, Treloar Haemophilia Centre, Lord Mayor Treloar College, Basingstoke and North Hampshire Health Authority, to Dr F G H Hill, Consultant Haematologist, Birmingham Children's Hospital, Birmingham) and copied to Dr.M.J.Strevens, Coventry & Warwickshire hospital. This letter has a URN of **TREL0000335_020** (Exhibited below, as **WITN46070012)** Dr Wassef states:

"Clinically he exhibits some of the stigmata of AIDS. He has had throat pains and difficulty in swallowing for more than one week in the past and lately at the beginning of June 83 and a cough for more than two weeks on and off. Examination of his superficial lymph nodes on 28.2.83 revealed palpable left axillary and bilateral inguinal lymph nodes. There is no change in the previous findings when re-examined on 14.6.83.

For your information, we have undertaken the enclosed AIDS related tests. We are repeating these before the end of term and will let you know the results when they are available."

302. In addition to obtaining my LMT medical records, my solicitor sought to establish my earliest HIV positive test result. Dr Wassef arranged for 3 frozen sera to be retrospectively tested. This was confirmed in a letter by Dr. Wassef, LMT to Dr. Jesson, Central Public Health Laboratory, dated 09 November 1988 in which sera samples 38428, 38427 and 38425 collected on 02 May 1984, 7 June 1983 and 19 January 1983 respectively were sent for HIV Antibody testing. The result was that all three sera were positive for HIV.

303. Dr. Aronstam confirmed in a letter to my solicitor that a test of frozen blood samples taken previously, had shown a sample collected on 19 January 1983 was positive for HIV. He also confirmed having frozen samples going back to 1980 that could be tested, but that there were cost implications in doing that. No mention was made of the AIDS Stigmata testing that had been performed in February 1983 and repeated later.

304. My solicitor made inquiries and I was told there would be a cost involved in testing further samples. I wasn't in a financial position to agree to that at the time, but some time later when I was in a position to have the samples tested, after the LMT haemophilia unit had been transferred to Basingstoke, I enquired if this could be done with a view to identifying when my last negative test was. The response I received by telephone was that the frozen samples were no longer available. The reason for that was that they had either allegedly been destroyed, although there was no record to confirm this, or had been used, possibly by the UKHCDO, to identify when HIV became prevalent in UK haemophiliacs.

305. Discovering this left me upset and very angry. There had been a clear legal interest in preserving the samples which had supposedly been stored for my clinical benefit, and, given my express interest, if my frozen blood samples were to be tested for some other reason, then at the very least I should have been able to expect the sharing any test results. This made me wonder whose benefit the samples were originally taken for and if tested, why I had been deprived of the results which could have answered my nagging need to know when I was infected, and may have been beneficial to my legal action. I also wondered whether the samples had perhaps been deliberately destroyed because they may have been incriminating in some way.

306. In any case, neither my parents nor myself were aware that so many blood samples had been taken for the purpose of freezing them.

307. This ability to retrospectively identify the point at which I tested positive for the presence of HIV, and the numerous frozen samples going back to 1980,

confirms the fact that Dr Wassef & Dr. Aronstam had full knowledge in 1980 that there were definitely concerns over the risks of blood borne viruses associated with American Factor VIII that may subsequently need to be tested for. Therefore, he had dishonestly lied to my mother when she raised concerns with Treloar's after hearing information about the AIDS bug in the news. Why?

308. This also raises a further significant question. If Dr Wassef and Dr Aronstram at Treloar's had suspected I was affected by AIDS in February 1983, before I started the Bonn protocol, but it was only in the spring of 1984 that they had sat me down in the doctor's office to tell me that there was something wrong with the blood, couldn't this also be considered dishonest?

309. There is a question mark over why Dr Wassef and Dr Aronstam continued their use of American Factor VIII product during the Bonn Protocol, despite having become aware of the knowledge of the risk of AIDS associated with American Factor VIII. As American doctors started to limit blood product use in some clinics, concerned by the risk of AIDS, I was given substantial units of Factor VIII between 1983 and 1984.

310. Amid the various treatments received at Treloars, I vividly recall a thought provoking moment about a comment made during one of my infusions for a bleed. I am not aware and have never managed to establish to which product it relates, but as Doctor Wassef began infusing me, he said to me "*This is good clean Scottish product you're getting today Mr. Peaty.*" I was in a lot of pain at the time so didn't question it, but the word "*clean*" struck me as odd. I remember thinking "*does that mean the other products I get aren't clean then?*" The comment made no sense to me. I trusted the doctors would not give me anything 'unclean' so I dismissed it. It makes me wonder now exactly what they did know about how unclean the products really were.

311. Why did they make the decision to continue to treatment me? Why did they not stop the Bonn trial in the interests of safety? It was the time period that is concerning to me. Why did they carry on, at a time when they knew there

was blood borne virus surfacing? I have so many questions. There are so many things that just don't sit right with me, and not because of hindsight, but because of the knowledge available and choices made at the time.

312. Activated pro thrombin complex concentrate therapies that were effective in the presence of an inhibitor were in their infancy around this time, but they offered hope of controlling bleeds where before there was none. The possibility of removing my inhibitor with high dose prophylactic Factor VIII, with all the benefits that could have brought, was also emerging. The excitement over these developments, in part, may explain why they were embraced so over-enthusiastically and with less caution and due diligence which should have been expected.

313. Despite being infected by January 1983, as a result of pushing ahead regardless, Dr Wassef and Dr Aronstam could still have potentially super infected me with multiple strains of HIV and HCV (and other viruses) during the process, and would in any case have additionally magnified the viral load to which I was exposed, which again, raised unethical and illogical issues. It was like rolling the dice.

Views on Lord Mayor Treloar College

314. On the whole, Treloar's is a paradox that puts my head in a spin. It was a place that enabled me to grow and gain confidence and independence, a place where friendships, love and life-long bonds were formed. It instilled belief that I could succeed and thrive in the outside world despite the inevitable challenges. It was a very special place that despite everything I would not wish to delete from my life.

315. The relationship with the doctors was so different to the norm. I was fond of them. As I would see them on such a regular basis formally and informally I thought of them as friends. They were also part of my 'Treloar family'. I talked with Dr Wassef about many things, including whether he thought a career in medicine was remotely realistic for a person with haemophilia as

severe as mine or whether I should pursue something in the rapidly growing field of computing when I left Treloar's. We would discuss my future. As I have previously mentioned, he tried to give me some insight by bringing in his medical school notes to show me what was involved.

316. The attitude that the Treloar's doctors portrayed, was that they were passionate about the treatment and care they were providing to the lads. It wasn't so long ago that there was no effective treatment and I believe that they genuinely wanted to make the day-to-day lives of haemophiliacs better. They were interested in treatment regimes that reduced bleeding episodes and protected against long term joint and muscle damage. This included trying treatments that pushed the boundaries in pursuit of restoring as near normal a life as possible.

317. At Treloar's the facilities and the care we received was undeniably exceptional, not like anywhere else in the NHS. The access to regular physiotherapy and hydrotherapy was second to none. It is the sort of support I have sought since but never received once I left Treloar's. The teaching and care staff also had a greater awareness and knowledge of haemophilia than any setting I had encountered before. This helped them to deliver a good education and social setting with the understanding of when to seek medical assistance that was close at hand ready to intervene or offer advice.

318. It remains to this day a unique educational and haemophilia centre arrangement that is unlikely to be repeated. The haemophilia students gained instant access to doctors and treatment of their condition day or night on a much quicker basis than we ever received outside of the college. Usually you could see a doctor within an hour of a bleed starting, even outside of normal working hours.

319. Bleeds were meticulously monitored and recorded and there was never any problem with access to treatment if prescribed; cost and supplies were never mentioned as issues, unlike at my home treatment centres. There were no barriers on availability of all forms of factor concentrate it seemed. It was

readily available. From the moment I arrived, my haemophilia management went from one of treatment abstinence to a mind-set intent on trialling existing and new treatments to evaluate their success and seek out a better treatment regime to prevent bleeds from causing long-term deterioration of joints and muscles with the aim of improving quality of life.

320. However, there was a lack of definition between where the college and its educational arrangements lay, with its own sickbay and physiotherapy facilities, and the crossover of NHS medical arrangements, which used those support systems and accommodation. I could not tell whether the Treloar Haemophilia Centre was an official centre of the NHS in its own right, or whether, it was in fact just an extension of the college.

321. On a day-to-day basis I didn't even think about the distinction, the medical centre (Sickbay) was just at the end of my boarding house corridor should I need medical help and other children without haemophilia would go to the same place for any medical problems they had. Hence the confusion.

322. The way treatment was administered without the apparent need to consult anyone else still makes me wonder who was our guardian at the college? Our parents? Was it our housemasters? Perhaps the headmaster? Or, as it felt sometimes, did the doctors just treat us children as 'adults,' and in that respect, received consent for treatment from us?

323. The freedom for the doctors to do, as they deemed clinically justifiable seemed to be inherent in the way the centre was set up, almost like being an inpatient in hospital. The need to consult parents about their child's treatment and gain their consent was rarely mentioned and despite the distance from home, my parents were rarely, if ever, updated on my haemophilia management unless they contacted the doctors themselves. The only regular feedback was a small report sheet in the college's end of term report that went to our parents.

324. I have a consistent conflict going on in my head when I think about Treloar's. I have a picture of two doctors who were generally nice, apparently well intentioned and interested in getting to know all the lads, but, the care we received I now perceive as much closer aligned to research and a big experiment. There was clearly an issue with how the doctors interpreted the boundaries of consent and the balance of risk to benefit. It seems to me they had freedom to apply whatever clinical judgement they chose without question or oversight.

325. Did Dr Wassef and Dr Aronstam carry out the trials and experiments to benefit us? Or, did they do it for their own gain to break grounds of science? Perhaps it was seen as a complimentary situation in which a combination of these two coexisted?

326. What I am clear about now is that I was continually bombarded with treatment after treatment, trial after trial, different batch after different batch, it was not just a one-off treatment, it was not used with any caution or concern and it completely contradicted the management of my condition previously applied at my home centre. Given the known risks of large pool sizes employed in America, the state of viral knowledge and lack of concentrate pasteurisation, the approach the doctors took is simply illogical to me. I cannot fathom the paradox between the apparent care the doctors seemed intent on providing and the wilful blindness, or recklessness, with which the use of virus containing commercial concentrates and trials were lavishly and haphazardly used.

327. I visited Treloars after leaving, toward the end of the 1980's, and on separate occasions managed to discuss briefly with both Dr. Wassef and Dr. Aronstam the horrendous outcome experienced by the boys that attended Treloars.

328. Dr. Aronstam seemed a shadow of the former formidable man I knew. I gained no greater insight as to why treatment and trials were used the way

they were at that time but after we spoke and I left him in his office a simple remark had been indelibly imprinted in my mind; "Sorry, we got it wrong".

329. Dr. Wassef by contrast insisted they didn't know the dangers. I asked how that could be given the state of knowledge at the time about hepatitis and warnings of AIDS, surely they realised there was a serious risk? I received no response; he looked forlorn and saddened and seemed to be at a loss as to how to respond. The exchange provided no answer as to how they got it so very wrong.

330. Dr. Aronstam and Dr. Wassef are no longer alive for the Inquiry to hear their explanation. It is one of the elements of this scandal that will likely prevent full closure for me. The length of time it has taken to obtain an inquiry and explore the truth behind the façade has ensured that key witnesses can no longer be questioned as to their thinking, their intentions, and their perceived justification for their actions.

Pharmaceutical Company involvement in LMTC

331. Between 1979 when I commenced my education at Treloar's and 1984 when I left, the Treloar Haemophilia Centre attached to the college was substantially upgraded and extended on Treloar Trust grounds. There was a new access road, new entrance to the haemophilia centre, with a new waiting room, new consultation rooms, offices, and a lab to one side of the site and at the other end of the existing sickbay, an extension that provided additional inpatient rooms and care facilities for the college. It was also noticeable that the college boarding accommodation and educational facilities were substantially developed shortly after the medical centre had been completed.

332. The nature of the haemophilia treatment, trials and apparent close relationship with Pharmaceutical Companies has given rise to question marks over whether the developments were funded by Pharmaceutical

Companies and also whether the College benefited in any way from the valuable research data that was undoubtedly generated at the Treloar haemophilia centre.

333. Treloar's as a setting was beneficial for all. The boys, the Pharmaceutical Companies, the MRC, the UKHCDO, the DHSS and Treloar's. It was beneficial for the boys, setting aside for a moment the catastrophic viral contaminants, as it meant we had access to an abundance of blood products and medical expertise for the treatment of our bleeds whenever they were needed.

334. Treloar's was unlike any other school or medical facility. It is not often that such large concentrations of haemophiliacs of around fifty to sixty students are housed in one location. All of these individuals needed treatment for their bleeds on a regular basis, of which, their treatment regime was not as regulated as if they were under the care of any other NHS hospital. The setting afforded the ability to closely monitor clinical response to any treatment used and would generate substantial valuable clinical data.

335. Had the Pharmaceutical Companies recognised the extremely focused group of accessible individuals within the college, and made donations to the college for any particular reason? How was it that cut-price products were so readily available, was it offset by some other valuable benefit? Did the other organisations like the DHSS, UKHCDO and MRC benefit from the statistical and research data generated?

336. I have spent a lot of time wondering whether this was opportunistic for the Pharmaceutical Companies to use Treloar's as a hub of experimentation and testing of their products, for both scientific advancement and profits. It was the perfect place for them to carry out studies with a ready supply of study participants. Were there any protocols about how children were inducted into these studies? Were their parents told about the varied treatments going on with their children? Was formal, recorded consent ever obtained or did the doctors act in loco parentis themselves? If so, were the parents aware and

agreeable to this arrangement? Was the centre set up to run that way with the cooperation of the DHSS?

337. It may not have been the doctor's at Treloar's who were personally benefitting, but maybe the Treloar Haemophilia Centre. The Treloar Haemophilia Centre doctors aspired to be at the leading edge of taking haemophilia treatment forward, and to offer a superior service where the treatment flowed more freely. Treloar's was more remote from other NHS Centres so they had more freedom to explore clinical trials, and to provide free flowing treatment as there were fewer apparent funding limitations.

338. Dr. Aronstam also had close ties with Professor Savidge at St Thomas' Hospital, London and seemed to me to aspire to the type of ground-breaking, maverick, he was often described as.

339. Recalling the conversation with Dr Aronstam when I visited Treloars after I left, he mentioned that after AIDS unfolded, a number of drug representatives visited Treloar's and that he had sent them packing because of their dirty product. This just went to show that even after the doctor's had become aware of the risks associated with blood product treatment, there were obviously still deals going on with pharmaceutical companies; perhaps to trial new heat treated products?

340. Even to this day, if it were somehow possible, I would want to go back to Treloar's and speak to Dr Wassef to ask him the many unanswered questions I have surrounding my treatment at Treloar's, particularly in light of the discoveries I made in my medical records later. I would want to ask him; who took the decision to carry out trials at Treloar's on the students? And, why they decided to carry out trials on me and other patients at that time? Also, whether the treatment used was approved for such use, was it licenced or experimental? Why were trials not stopped and the products returned? I would also like to know why the government and/or manufacturer did not recall the products when the risks became apparent?

341. I also question whether anyone has looked at the finances at the college, where did the funding come from, what contracts, if any, were put in place and agreed with the suppliers of the products we received? Was there any DHSS oversight? What were the financial arrangements that resulted in the Haemophilia Unit obtaining such a substantial extension to the medical centre?

342. Other Infections - Official Diagnosis of HIV & Examples of Impact
Exhibit WITN4607026 refs.

343. The year before leaving Treloar's, because I had transitioned to adulthood while at college, Dr. Hill at Birmingham Children's Hospital informed my mother that he was making arrangements for me to be transferred to an adult centre.

344. My mother enquired if Coventry would be suitable as it was closer. The doctors at Coventry were contacted by Dr.Hill and agreed to take on my care with the understanding that I would need the inhibitor by-passing treatment FEIBA to treat my bleeds in future.

345. Thereafter, initially in the school holidays but later when I left Treloar's, I attended the Coventry Haemophilia Unit, based at Coventry and Warwickshire Hospital, Stoney Stanton Road, Coventry. Later the unit was transferred to the main site at University Hospital Coventry and Warwickshire ("Walsgrave"), Clifford Bridge Road, Coventry, CV2 2DX, under Professor N.K Shinton and Dr. M.J. Strevens.

346. During the Christmas holidays 1983 Dr.Strevens reviewed me and took 'routine' bloods. My medical records show, unbeknownst to me, these included a repeat of the Hepatitis B and 'AIDS Stigmata' tests performed by

Treloar's, with results from tests dated 21 December 1983 being directed to immunology for analysis.

347. This is confirmed in a letter from P.M.Chandler to Dr.Strevens dated 19th January 1984, in which he confirms positive results for HBV core and surface antibodies, and essentially normal immunology except for raised IgM levels. I have a copy of the letter if required.

348. Four months after leaving Treloar's, in November 1984, I was admitted to Walsgrave with severe right side abdominal pains. Despite being in extreme pain, very pale and unwell there were no clear signs as to the cause. An unidentified abdominal bleed was suspected. For some reason I am unaware of, over the next five days the doctors treated me with Factor IX not FEIBA (perhaps they had seen reference to Treloar's trying the product with apparent 'good clinical response'?). Unsurprisingly it again had no clinical effect and a week after admission my condition had worsened and my haemoglobin had fallen to 6 g/dl; I now required 3 units of blood to be transfused. My condition now included signs of haematuria too.

349. Finally a decision was taken to try a single dose of FEIBA. It had a beneficial effect and my condition gradually improved until I was discharged a further 5 days later. Ultimately, there was no conclusive diagnosis of my suspected abdominal bleed from the scans performed. Apart from noting my enlarged spleen, the only indications of interest suggested an ilio-psoas muscle bleed was a possibility. It appears the discharge plan had been to review me in Dr.Strevens outpatient clinic two weeks later.

350. During my stay in hospital, I recall a doctor checking on me late one evening. As I was awake he asked if it would be okay to talk for a while about my haemophilia. I agreed and we spent some time talking about my past bleeds, the various aspect of treatment and my recovery.

351. Our conversation turned to the subject of the AIDS virus and the reports of haemophiliacs being affected. All of a sudden, the doctor remarked that he'd

been looking at my medical records and noticed I'd been 'affected' and asked how I felt about it. I thought he meant affected in the sense that there was uncertainty and concern I may be infected because of the use of Factor VIII I'd received for my treatment; By that point in time I had heard from TV reports that the virus that lead to the development of AIDS had been identified and was being called LAV or HTLV III and that they were developing a test for it. I was acutely aware that if you had it then it was considered a death sentence.

352. Responding to the doctor I said something like "I know they've identified the virus and we are waiting for a test to make things clearer but with all the treatment I've had I expect I will have it".

353. His response sent my head into a spin, it was something like "*yes, I see you've been tested.*" I remember being confused when he remarked about a test that showed I'd been affected because I meant they were waiting for a new specific test to be developed but his words indicated that this had already happened and it was known that I was affected. The remainder of our conversation is something of a blur. My mind went over that part of our conversation through the night as though I must have misunderstood, but the longer I thought about it I could see no other interpretation. It seemed we had misunderstood each other and in so doing he'd let slip, that I was infected with the virus that leads to AIDS.

354. Afterwards, I remember feeling eerily calm, as I contemplated my new reality. This was the first time I had confirmation about my HTLV III diagnosis officially. I wasn't completely surprised, as at this time, I had already put two and two together. Between the information on HIV and AIDS on the news, and the debilitating symptoms of flu I had experienced between 1983 and 1984, I had already suspected that I had contracted HTLV III.

355. Events later unfolded that made me question whether the doctor was referring to a newly requested HTLV III test, or, as I now suspect, to the

AIDS Stigma tests performed by Treloar's and repeated by Coventry. In either case I was left with the impression of having been infected.

356. Unbeknownst to me until a review of my medical records, my discharge summary and lab test slips show my first HTLV III test was performed while I was an in-patient. A positive result on a sample dated 23 November 1984 is reported on 14 December 1984. The HTLV III Test was reported by the Virus Reference Laboratory, Colindale, London using Radio Immunoassay, which I understand now, was a UK test being developed and trialled at that time.

357. The follow up appointment was not with Dr. Strevens as expected. I was reviewed instead by Dr.J.Oakley, Senior registrar, on 21 December 1984. The doctor notes a good recovery from the suspected iliopsoas bleed, that my spleen is still palpable and blood had been taken for testing my liver function; there is no mention of the HTLV III test, the result or of me being told anything about it.

358. On 25 April 1985 my mother accompanied me to Coventry & Warwick Hospital where I requested to see Dr.Strevens. Mr.Lavington who was a lab colleague told us that he would come and see us as soon as he was available.

359. At Treloar's it had been emphasised repeatedly that all bleeds should be reported immediately, assessed and severe bleeds treated early with FEIBA. However, I was frequently experiencing the denial of treatment by Dr.Strevens at Coventry & Warwickshire hospital on the grounds of cost, despite him assuring Dr.Hill that he was prepared to take on my care including treatment with FEIBA. The use of FEIBA did not appear to be related to concerns for its safety as I was being assured the treatment was safe on occasions when I was given it. This may have been because heat treatment that inactivated hepatitis and HIV was introduced around this time.

360. I wanted to understand why treatment was being withheld, and to find out how to access dental care. I also needed to know what had become of an

operation professor Savage at St Thomas' had been planning to enable me to walk again. I was told he was in the department and I should wait for him.

361. Two hours elapsed and he had not appeared. In frustration my mother went looking for his secretary. She discovered Dr.Strevens sat in an office and was told he had no intention of seeing me. My mother insisted he explain what was going on with my treatment and his curt reply was that it was very expensive stuff and he couldn't afford to treat all bleeds. He added, "besides there is the issue with his exposure to the AIDS virus." My mother wanted to know what this meant, and he said they didn't know yet which people exposed to the virus would get AIDS and die as a result. After asking about dental treatment and for an update of the operation we left the hospital. My mother relayed to me what had been said. I was shocked at the conversation as the news was given without any consideration of its potential impact or whether my mother was even aware.

362. Soon after, on the afternoon of Sunday 28 April 1985 I developed a severe wrist bleed and I attended Walsgrave hospital. I was faced with a registrar that was covering Dr. D'Costa the usual haematologist, for 4 weeks. Worryingly he didn't have a clue about my haemophilia condition and kept saying he was arranging for Factor VIII, despite me informing him I had an inhibitor and that was not the appropriate treatment. Eventually, as I grew more concerned about his lack of understanding, a senior nurse came up to me and whispered "Don't worry we won't let him touch you!" She intervened and a dose of FEIBA appeared that with difficulty, because of the bleed, I had to prepare and infuse myself. I was then sent home to rest.

363. On the 30 April I again attended Walsgrave for further treatment. I arrived at 11.15am but, as was often the case because the FEIBA was sent over from Birmingham QE hospital, it took until 6.30pm to arrive and infuse. A follow up appointment was made for the 1 May.

364. By the 01 May 1985 the bleed had not settled and had worsened further. I was reviewed by Dr. Strevens and this time was admitted to Walsgrave. My

right wrist was by now extremely tender, aching and very stiff with almost no remaining range of movement. The assessing ward doctor, after obtaining instructions from Dr. Strevens, again treated me conservatively with pain relief, ice packs and, additionally, a back slab splint, but without the use of FEIBA. The bleed eventually resolved and I was discharged on 10 May 1985.

365. It is noteworthy that nowhere in my medical records does it show that I have been informed of my HTLV III status. Dr. I. Shackleford demonstrates this when he records in my medical records on 03 May 1985, in addition to his clinical review, that he is unsure as to whether my HTLV III status has been disclosed to me and he asks the question "Does the patient know about his HTLV III status?"

366. My recollection is that the next time I saw Dr. Strevens, he questioned whether I had received the results of an HTLV III test done on 23 November 1984. I told him I hadn't been told the result. He then informed me I should have been told before, and that I had tested positive for HTLV III, the virus that leads to AIDS. He added it should have been followed up with a second test to be certain.

367. Following my mother's conversation with Dr.Strevens on the 25 April, he reviewed my access to an adult dental service as none had been established since my return from Treloars. Dr. Strevens arranged for me to be seen by Mr.J.G.Burland, Consultant Oral Surgeon, Coventry & Warwickshire Hospital for a routine dental check up on 30 May 1985. In his letter Dr.Strevens informs the dentist of my HTLV III status and outlines the official guidance that the same precautions as with Hepatitis B should be used. That appointment is the first time I recall talking with another clinician outside of the haemophilia unit about having just found out I was HTLV III positive.

368. There was no counselling or explanation given to me of precautions that should be taken with a partner when my diagnosis was provided; the diagnosis was delivered in a very matter-of-fact way. The crushing revelation

was only made bearable by my own deduction from news coverage relating to AIDS and cases affecting haemophiliacs, plus my memory of the prolonged flu-like illness I had at Treloar's coupled with the late night discussion with the doctor in which I had been unwittingly alerted, all of which had given me time to reflect on what it meant for me.

369. The subject did not arise again until an outpatient appointment on 30 September 1985 when it was realised that a confirmatory test had still not been done. An HTLV III blood test was then done immediately to confirm my status and the Virus Reference Laboratory, London, reported a positive result on 01 October 1985. I believe I was told at my next routine clinic appointment.

370. Thereafter, my records show a letter from Professor N.K. Shinton, Coventry and Warwick Hospital was sent to my GP, Dr. GRO-D, on 04 November 1985 to inform him that because of my treatment with Factor VIII concentrate that I carried a risk of infection with HTLV III and should be regarded as a potential carrier. He went on to say that laboratory tests were *'being performed'* and any significant results would be reported to him. Also, if I showed any sign of associated illness then they should be reported to the haemophilia centre immediately. The letter did not mention the confirmatory test results already obtained.

371. Whilst initially, my diagnosis of HIV did not shock me, it was none-the-less a source of despair. I had suspected that I had contracted the viral infection due to the symptoms I'd displayed, but after the news sunk in it began to knock me for six. My illness and night sweats suddenly made sense, I realised I really may not live very long. My world disintegrated.

372. I had heard so much on the news about persons who contracted HIV had subsequently developed AIDS and died. I thought to myself, it's going to be the end isn't it. This is AIDS, people die of AIDS. That was all we knew at the time, as it was such a new infection, and no one knew very much about it.

373. I discussed my diagnosis with my mother who relayed to my father what we knew. I do not think they wanted to show me what they thought, but I knew they were distressed and fearful for me. It was the unknown but the situation looked dire. They have since told me that they feared the worse, but would try to be as positive and supportive as possible. I for my part, wanted to protect them from hearing every little thing that caused me concern that my condition was deteriorating.

374. The relationship with my haemophilia consultants felt as though it was deteriorating; to my mind this was because of the stress caused by contaminated treatment. It seemed like there was even less willingness to communicate whatever problems were being considered and every time I reported a bleed I was told to rest and treat it with ice packs and analgesia; it seemed the mantra of reporting and treating early had been rejected. The recurrent excuse was that the treatment was expensive and they couldn't afford to treat me. I recall seeing a UKHCDO communication to centre directors that suggested using this line to avoid treating, rather than, presumably, highlighting the risks associated with the products.

375. In November 1985 I made enquiries about how to have my doctors management of my condition reviewed. I needed to know if it was appropriate to withhold treatment. If it was on safety grounds this would have been understandable, but it should have been communicated to me, however, I was aware that concentrates were now being described as virally safe because they were being heat-treated and I wondered whether it was cost or safety that was the reason, and if it was cost whether this was appropriate.

376. I discovered I could have my medical treatment reviewed by the Health & Safety Executive and wrote to them to raise my concerns. **Exhibit WITN4607030 refs.**

377. The only correspondence relating to this matter contained in my medical records that confirms this, is a form dated 07 November 1985 in which I give permission to my doctor to share my medical details with the Health & Safety Executive, Employment Medical Adviser. **Exhibit WITN4607030 refs.**

378. I wasn't given a detailed explanation of their review, but my care changed a short time later and I received FEIBA more frequently when I presented with a severe bleed; the doctors understood and were reassured that I would continue to treat less-severe bleeds conservatively at home.

379. The sense of despair that had been growing since Dr. Wassef has informed the Treloars boys that there was a 'bug in the blood', had deepened as my knowledge grew and I experienced the effects of being infected. The earliest portent of the impact and stigmatising effect came in July 1985 shortly after hearing the first HTLV III test had confirmed my infection. Treloar's had arranged a trip to the U.S.A. that would involve a tour from Portland, Oregon down to San Francisco over a three-week period. It would be a last chance to spend time with some of my friends before we went our own way in life.

380. Being a haemophiliac involves carrying any treatment you may need with you as well as medical letters informing Custom officials the reason for the medication and telling medics what to do in an emergency. I had my standard letter covering my haemophilia; it did not mention any of my viral infections.

381. As our flight approached our destination the flight crew handed out additional immigration forms for us to complete in relation to our entry to America. These forms, were a newly introduced process I believe, and wanted to know if the person was affected by AIDS, and made it clear that being affected was a reason that could result in being refused entry. I was thrown into a complete panic. I felt like a pariah and was paralysed as to how I should answer their questions without unnecessarily ruining a trip that had taken substantial effort to arrange. I had no advanced warning that I would be put in this position and no one to consult as to how I should respond.

382. Ultimately I decided to use a technical loophole, as I saw it, to say I had not got AIDS and therefore considered that I could say I was not in fact affected by it. I was really worried that my answers might land me in trouble, but in the end, the passport checks went through without incident and the trip went ahead as planned. However, I felt like a criminal for the first time in my life.

383. By the next occasion I travelled to America, some years later, I found I had to disclose my HIV status before travelling and was therefore no longer eligible for a visa because of my positive status. Instead I had to go through a long-winded process, that no-one else in my family had to do, to obtain a special 'visa-waiver' document allowing me entry for a limited time, but not as long as my family were permitted to visit for. We were visiting family in America and Canada, but I wasn't allowed multiple visits between the countries, unlike the rest of my family. I felt the special document, stapled in to my passport, and different treatment marked me out as someone less welcome, even undesirable, than everyone else. It was highly stigmatising.

384. Another early experience of the fear and prejudice AIDS was provoking was witnessed by my mother and relayed to me. The weight of my potential infection, and then confirmed infection, had been a great source of distress. She needed to talk about it to someone but was unsure how friends would react.

385. My mother had begun working for Social Services, community care in 1983. One afternoon she returned from her work and was clearly agitated, upset and fearful of what she had heard that morning. Her employer had held a training course and part of it included precautions in relation to AIDS.

386. The attitudes she heard expressed and derogatory way her work colleagues reacted to the possibility of caring for someone with AIDS chilled her. Some of these colleagues lived nearby, and she suddenly realised she could not talk to her friends, neighbours or colleagues about what had happened to me; she couldn't cope with the disgust and stigma she had already seen

while they were unaware of our family having been affected. Non-the-less, perhaps because they made associations with haemophilia increasingly being associated with AIDS in the press, friends did dwindle away, and we both realised we must keep the burden of our situation to ourselves.

387. It was around this time that I also stopped trying to spread awareness of haemophilia to anyone that was interested in listening, as I feared an adverse response. I was aware from old friends and press reports of the extreme experiences visited on some sufferers of AIDS, whether Haemophiliac or from the gay community.

388. The pressure of living with the AIDS virus was unrelenting. I couldn't see any future for myself. So over the Christmas of 1985 it came as a surprise and with a lot of trepidation when I met someone that was interested in getting to know me romantically. I grappled with if, when, how to tell her of my infection. Too soon and she may just cut and run, too late and it would seem unfair to have let her develop feelings that she may not then feel able to pursue.

389. One evening I bit the bullet and told her. She was very calm and seemed to accept the situation without any great concern; unexpectedly this turned out to be a source of great concern for me too! The relationship developed and we became intimate, but always on my mind was her safety and the need for precautions to avoid her becoming infected too. I had learned the risk of sexual transmission not from my doctors but from the press and articles I had read myself. Despite this, toward the end of January 1986 the barrier protection we had been using failed. I was distraught at the possibility of her being infected and sought advice from Professor Shinton at Coventry & Warwickshire Haemophilia unit.

390. When I attended the face-to-face consultation with Professor Shinton on 27 January 1986, I explained that I was worried that the barrier method we had previously been using to practice safe sex had been compromised.

391. Professor Shinton proceeded to tell me that the chances of passing on HIV sexually were very slim to virtually none existent, so if we wanted to go ahead and have an active sex life it would be fine. The advice I was given was something along the lines of "*there is no undue call for concern. HIV is difficult to catch so that the chances of sexual transmission during normal sexual relations are so low at to be virtually nil. I don't think you need worry.*" He didn't mention any risks associated with Hepatitis at all.

392. The consultation on 27 January 1986 is recorded in my medical record case notes with the word "Counselled" next to the entry. I have a copy of this.

393. At the time, I thought that this was a very odd piece of advice to have received, as if anything, I expected doctors would usually air on the side of caution with regards to preventing any transmission of blood borne viruses. I wondered if I had misunderstood the risks, however, this advice clearly went against the government guidelines that prevailed at the time, which was to practice safe sex.

394. My girlfriend was not very impressed with me for having raised the level of concern to such a degree. This made it difficult when, after briefly taking his advice, I decided that it did not seem right and I would not follow the advice given by Professor Shinton, and would continue with safe sex practices.

395. Additionally, I offered to enquire about having my girlfriend tested at my clinic, just to ensure that I had not unknowingly passed on HIV to her. Professor Shinton agreed to do this if I really wanted, but because of the period required for seroconversion it would mean a stressful three month wait before a test could be done.

396. Over the coming weeks it felt like this had come between us; I knew she was desperate to have children but I didn't have a clue how that would be possible with me without her becoming infected too. By the middle of February the relationship ended and she said she would go to her GP for a test if she felt the need.

397. I feel as though the advice Professor Shinton was providing his patients was bad, even disastrous, advice. Although via hearsay from someone I met in the clinic, I gathered this had worked out far worse for some others. I can recall being told about one couple he gave the same advice to, who wanted to try for a baby, apparently, both the mother and baby became infected though I have no way to confirm this.

398. The reasons for his advice seem odd to me; either Professor Shinton was trying to do trials for himself to see what would happen with regards to practicing unsafe sex or he was poorly informed. However, at the time he was attending many UKHCDO meetings so he should have known about the risks and government advice at the time. I have seen his name on a number of UKHCDO meeting minutes in attendance.

399. Yet another source of stigma I felt at being infected with HIV, that amplified the isolation, despair and perception of disgust from others, came from the NHS itself. Shortly after the concerns of AIDS arose in relation to haemophilia, the admission procedures changed and for most of the 1980's whenever I was admitted to Walsgrave Hospital I was marked down as requiring a side room, barrier nursing and HTLV III/HIV precautions. There are notes to this effect on my medical records. Often this meant there were no suitable rooms available on the haematology ward where I would usually be admitted and I would instead be relocated on an isolation or IDU ward.

400. One particular admission stands out, but reflects the general experience and attitude toward me at that time, I believe as a potential AIDS carrier.

401. On 31 August 1988 I had been admitted with a severe bleed into my knee, pains around my kidney area, haematuria and a very high temperature. I recall I still had the effects of pre-existing bleed in my arm, possibly the wrist, too. The combination of bleeds meant I was very immobile, in a lot of pain and restricted to bed rest. Without assistance even getting to the bathroom was an impossible feat.

402. Over the next four days meals were put on the side table and pushed through the door toward me and drinks were only infrequently offered. Previously they would have been brought in and set up within easy reach. There were no offers of assistance to carry out personal care, even if requested. The nurses did not want to come into the room it seemed except for the most exceptional of needs. Even use of the toilet often meant I had to wait for family visits to get assistance. I had to use urine bottles but they were piling up and not being removed or emptied until my mother arrived to do it. It felt like the staff were opposed to coming in to me, I wasn't even being provided with regular ice packs as the doctors had requested. I felt like I'd been stuck in a room out of their way and forgotten.

403. My parents even got told off for not observing the additional barrier nursing hand wash procedures in case they 'caught my infection'. My mother's response, that I normally live among the family without the need for such precautions, fell on deaf ears.

404. Because of the neglect, I asked my mother to see if she could find the Floor Ward Manager that knew of me from previous admissions. She was not on shift but a message was left for her. After four days without receiving a wash, or the bed being changed or made I was relieved when the floor manager's friendly face poked around the door to see how I was. After hearing the treatment I had received she went away to challenge the ward staff; she did not seem at all impressed. I'm unaware of what was said or agreed, but in any event the ward nursing staff did not come to assist me, instead the floor manager herself came back a number of times to provide a bowl of water and assist with having a wash, changing my clothes, refreshing the bed clothes and toileting. She also arranged to get the ice packs I needed. I felt like a pariah even in the setting geared toward infectious diseases and became very depressed. I was eventually discharged on 06 October 1988.

405. This type of crushing, demoralising treatment was a repeated occurrence until the procedure was changed and it was no longer deemed necessary to

send me to an isolation ward. Thereafter I was still not permitted in to the multiple bed bays but was instead located in a side room within a standard ward.

406. Another cause of anxiety was related to inadvertent disclosure of my condition and the potential consequences. One particular occasion arose at the end of 1986 in an unexpected way.

407. On 27 October 1986, with no further communication being received from Professor Shinton about their laboratory tests, and having learned from my mother that I had been told I was infected, Dr. GRO-D our GP, wrote to Professor Shinton for clarification.

408. Professor Shinton replied on the 11 November 1986 confirming that I was HIV positive and expressing that this should come as no surprise given the considerable amount of blood products I had received over recent years. He also says the "DHSS has strongly recommended that information about HIV status not be conveyed to anyone without the patients consent". This permission, he says, has now been obtained.

409. This exchange of letters, or perhaps even the Treloar's mention of AIDS Stigmata, became the precursor to a breach of confidentiality that was to be devastating to my family and me.

410. My mother and sister had cause to see the GP on 12 March 1987. This must have been the first time Doctor GRO-D had seen my mother since receiving notification of me being caught up in the blood product infections because when she entered the doctors office, Dr. GRO-D immediately arose to receive her, and without thought for my sister's presence, began to express his sympathy for 'Joseph being infected with HIV'. My sister was understandably shocked and upset because she didn't know; I had wanted to inform her in my own time when I had come to terms with it and could cope with the emotional turmoil it would create.

411. My mother was thrust in to a situation she wasn't prepared for by our GP's unprofessional disclosure. After their consultation my mother and sister talked and consoled one another for some hours before returning home. Again there was no professional counsellor available for either my mother or sister.

412. My sister has never mentioned my infection or the way she found out about it but I feel the way it was disclosed damaged our relationship. I'm certain she feels hurt that she hadn't heard about it from me, but I cannot reverse this now and feel very aggrieved that the option to talk to her was taken out of my hands by the unauthorised disclosure of my HIV status to my sister by my GP Dr. GRO-D

413. A further heart-stopping occasion with potential for unintended disclosure occurred while I was working within the education department of Coventry City Council. I have a medical ID bracelet which contains all essential medical information should I be in an emergency and unable to communicate. On one occasion the clasp had broken and I had not realised. The bracelet had fallen from my wrist somewhere within the offices. I realised as I was leaving for the night and a frantic search ensued. I had seen and heard of other haemophiliacs losing their jobs just because of the fear associated with AIDS. My heart was pounding, I could hardly get my breath for the panic attack and I felt sick to the core. After retracing my movements as best I could remember over two floors, without success, I had almost given up and resigned myself to facing some uncomfortable questions if it had in fact already been found, when I noticed it glinting on the floor near reception. The relief was immense!

414. While I was dealing with my anxiety and depressive episodes, I thought I was keeping as much pressure as possible away from my mother, although we had spoken about the disease progression and she was aware that I could go from seemingly healthy, mostly dealing with effects that were not obvious to others, to deaths door, in a scarily short time.

415. GRO-C

416. By 1987 I was told a newer HIV ELISA test became available and so on 30 November 1987 and then again on 27 May 1988 the doctors repeated my HIV tests to confirm the earlier test results showing my HIV infection; or perhaps the doctors used me to help validate the new test?

Establishing When & How I Was Infected Exhibit WITN4607026 refs.

Diagnosis of HIV

417. I cannot pass comment on what product or batch had caused my HIV diagnosis as fact. I have received multiple units of Factor VIII, Factor IX, Autoplex and FEIBA. I have been involved in many experiments and trials, to advance or evaluate treatment for my haemophilia for the majority of my life, including the use of animal concentrates. Therefore, due to the magnitude of my exposure to viral infection, it would be difficult to pinpoint the exact point at which I had contracted HIV. I do know I was a young man at the start of his adult life and a lot of my dreams and aspirations had come to a sudden end with the diagnosis.

418. Through a process of elimination, a blood sample taken whilst I was still at Treloars', frozen for retrospective testing and eventually tested in December 1988, produced a positive test result for the presence of HIV in January 1983. I would therefore have received a contaminated batch of blood product prior to January 1983.

419. This ruled out the Factor VIII I received during the Bonn Protocol that ran from February 1983 to June 1984, and the Factor VIII/Autoplex used in the second Autoplex Trial implemented in May 1983 and, also the Factor IX Trial that ran from October 1983 to March 1984. As I mentioned earlier, more precise identification of my HIV infection would have been possible if my frozen blood samples had not been allegedly destroyed or re-purposed.

420. On the information available therefore, it is likely that it was the Factor VIII I received as treatment for my cerebral bleed at the Birmingham Children's Hospital and John Radcliffe in June 1977 (although this would have represented an exceptionally early example of infection in the development of the UK HIV pandemic if true), or, more likely, either the single dose of Hemofil received on 11 January 1981 at Treloar's for a reason that remains unclear, or Autoplex and FEIBA I received in trials that I was part of during the period 1980 to 1983 at Treloar's.

421. Continued concentrate use after infection would also have added to my viral load which could have altered the severity of my infections.

422. No information or advice was provided either to my parents or myself before receiving any blood product throughout my treatment for my haemophilia surrounding the risk of being exposed to infection. My treatment with blood product commenced whilst I was a minor, therefore, such risks should have been provided to my parents. This did not occur. Instead, Dr Rizza referred to Factor VIII as a 'golden product', and other clinicians always highlighted the benefits without mentioning a viral risk.

423. With all that I now know I do consider that my HIV diagnosis should have been provided to me at an earlier point in time.

424. The results that could have been obtained from blood samples taken and frozen by Treloars going back to 1980 should have been processed and shared with me as soon as a viable HIV test became available, to identify my

earliest negative and positive tests. This would most likely have been in 1984. The cost of the testing should not have been an issue for me to bear.

425. Similarly, the results of any blood samples I had provided in 1984, when the Treloar's boys were originally told there was a 'bug in the blood', to be used we were told as a confirmatory exercise for the presence of what was later termed HIV, have also not since been communicated to me.

426. All these blood test results would have been more use to me, Birmingham Children's Hospital or Walsgrave, as opposed to just remaining within the knowledge of Treloar's, and later Basingstoke Hospital, or allegedly the UKHCDO, after I had left.

427. This is also true of the retrospective tests on stored sera I had undertaken in 1988 that showed I was infected in sera taken in January 1983 whilst in Education at Treloar's; this positive result for the presence of HIV was not communicated to me without the intervention of my solicitor in 1988.

428. I have, however, been told about the results of a blood sample which was tested on 23 November 1984, and had returned a positive result for the presence of HTLV III (later known as HIV) at Walsgrave. However, even this diagnosis, was not provided promptly, in an orderly, official capacity.

429. The registrar at Walsgrave was unaware that I had not been told of my tests for AIDS Stigmata or HTLV III previously, and had simply communicated this to me through a confused conversation. A registrar who followed me up in the outpatient clinic also failed to inform me. When my Haematology Consultant Dr. Strevens at Walsgrave eventually told me, around 6 months had elapsed. Therefore, I had not been provided with adequate information to understand and manage my infection promptly.

430. The way in which I had been notified of my HIV diagnosis was absurd. I had been tested for blood borne viral infections, or their markers, on a number of occasions, whilst at Treloar's, and at Walsgrave. Each time, I had not been

notified of the results, yet, it was noted in my medical records. I had experienced symptoms of HIV on a number of occasions, and yet, the reasoning behind this was not mentioned.

431. I had not been told any information about the risks of others being infected as a result of my HIV. I had to learn about the practices of safe sex through alternative means, which was confirmed by the government's guidance in the 1980's.

Other Infections - Diagnosis of Hepatitis C "HCV" Exhibit WITN4607027 refs.

432. In January 1993, at the age of twenty-seven years old, I attended a routine clinic appointment at Walsgrave. I recall originally being told of my HCV diagnosis very informally by Professor Shinton sometime after a blood sample had been taken in 1991 but before his retirement. (This is not documented in my medical records)

433. The information I was given by Professor Shinton was along the lines of "the Hepatitis Viruses will probably run from A to Z by the time they are all identified, but not to worry as your antibody just means you are immune." I believe the appointment in January 1993, unsigned in my case notes, may have been with Dr.Strevens and related to concern that I had not been told of my earlier test result. During this appointment, I was told that a blood test performed in 1991 had tested positive for the presence of HCV; I had also demonstrated previous infection with Hepatitis A I was told.

434. There are two notable symptomatic occasions in which I may have been exhibiting signs of a new and recent infection with HCV.

435. Firstly, as previously stated above within my HIV Dignosis, between the end of July and the start of August 1977, my health began to deteriorate and I exhibited signs of a hepatitis type infection. As previously described, I did have an infusion at the Birmingham Children's Hospital before I received

further Factor VIII treatment for a cerebral bleed at the John Radcliffe under the care of Dr Rizza in June 1977.

436. About 4 weeks after my first commercial Factor VIII infusion I had noticed that my urine was dark brown in colour, and that my stomach had become noticeably enlarged beyond normal size. When we questioned this with Dr Rizza, he said *"oh that would be the hepatitis."* When questioned on where I would have caught it he said "*It's in all the treatment*". This remark made by Dr Rizza suggests that the Factor VIII treatment I received in 1977 had been contaminated with hepatitis, and as a result, such an infection was the cause of my symptoms.

437. Dr. Rizza had tested me for HBV Antigen & Antibody on 20 June & 01 July 1977 with both tests returning negative results. I have copies of these tests if needed. However, despite his comments and my mother bringing my symptoms to his attention, Dr Rizza did not under take further testing before my discharge on 07 July 1977 and did not inform Dr. Mann at the Birmingham Children's Hospital. He also did not offer any advice about avoiding potential onward infection. The apparent incubation period, around 28 days, would suggest this wasn't a HBV infection but perhaps more likely HAV or HCV (NANB at that time).

438. Further tests might have confirmed or ruled out whether I was in fact positive for the presence of Hepatitis A, B, or, by elimination, non-A non-B, or whether my symptoms were due to something else.

439. There are question marks over this period of time. However, my medical records continue to record HBV surface antigen and antibody negative results up until the time I started at Treloar's in 1979 where, despite this, the doctors quickly noticed and recorded 'intermittently but markedly raised liver function test results'. This is suggestive of active chronic non-B hepatitis.

440. Secondly, towards GRO-C 1983 and GRO-C 1984 whilst I was aged eighteen years old I was suffering from hepatitis-like symptoms whilst I was

still at Treloar's. During this period, Dr Aronstam and Dr Wassef had commenced treating me in accordance with the Bonn-style Protocol they had established; of which, I was regularly being exposed to American Factor VIII. Additionally, I received several doses of Factor IX in another trial at Treloar's.

441. During this period, my health had deteriorated, of which, it was explained away as a common illness. However, hepatitis had not been mentioned to me by either Dr Aronstam nor Dr Wassef in 1983 when I attended the Haemophilia Centre at Treloar's.

442. Despite a HBV test also showing the development of a HBV surface & core antibody positive result in December 1983 at Coventry & Warwickshire Hospital, this was not addressed retrospectively or mentioned to me.

443. As a consequence of the aforementioned, I cannot say as fact, at what specific point I had contracted a blood borne viral hepatitis infection. Albeit, both of the above instances were referred to as hepatitis. I also cannot confirm as fact whether either instance was the cause of my HCV infection, as the specific type of hepatitis has not been affirmed as HAV, HBV or HCV; or any other type of hepatitis beyond the Inquiry's Terms of Reference.

444. There also remains the possibility that my initial HCV infection was a mild, symptomless event resulting from my receipt of blood and blood products during the period June 1977 until tested in January 1991.

445. Retrospective testing of the allegedly destroyed, or re-purposed, stored blood samples taken by Treloar's could have helped identify more precisely the date of infection had they been used appropriately in my interests.

446. Neither my parents nor I had been provided with any information or advice beforehand, of the risks of being exposed to Hepatitis A, B, non-A non-B/ HCV as a result of receiving blood products as treatment for my haemophilia. This includes by Dr. Mann and Dr. Hill at the Birmingham

Children's Hospital, Dr Rizza at the John Radcliffe, Dr Aronstam and Dr Wassef at Treloar's, and Professor Shinton and Dr. Strevens at Walsgrave Hospital.

447. When I was told of my diagnosis with HCV at Walsgrave Hospital in January 1993, I was not provided with any information that would have allowed me to adequately understand or manage my infection.

448. The medical professionals at Birmingham Children's Hospital, Treloar's and Walsgrave Hospital clearly knew there was something going on with regards to my health, yet they did not mention this to me. When I would attend my regular hospital appointments, they would flick through my medical notes, and not tell me information contained within the file such as my kidney function for example. All I would hear, was small remarks such as "*oh*" or "*Hmmm*" or "*Better look at that*" As we did not question doctors in those days, I was left uninformed and oblivious to what was going on.

449. I knew that the medical professionals at Birmingham Children's Hospital, Treloars and Walsgrave Hospital were all clearly carrying out tests on my blood. However, I had assumed prior to my diagnosis that they were monitoring my Factor VIII inhibitor levels, or my clotting activity. I could not have imagined that they were looking for evidence of viral infection.

450. I do consider that I should have been notified formally about my NANB & HCV diagnosis at an earlier point in time and that should have been recorded in my medical records.

451. Whilst inspecting my medical records, it has come to light that I was tested in January 1991 for the presence of HCV, and the results had returned as demonstrating that I had tested positive. However, this raises the question over why, if my records are accurate, I had not been told of my diagnosis until two years later, in January 1993?

452. I should have been formally notified in January 1991 with correct information about the nature of the positive test and the potential impact on my health, when the medical professionals at Walsgrave Hospital had become aware of my HCV diagnosis.

453. If I had been notified of my HCV diagnosis in January 1991, this would have allowed me to have taken precautionary steps in the interim, to prevent any risks to my family or friends of being infected via contact with my blood.

454. I also find the timing of the introduction of a new HCV test as particularly suspicious, coming as it did, immediately after the HIV settlement that required signature of a waiver that unexpectedly included "Hepatitis Viruses".

455. At the beginning of 1997, during a visit to Heartlands HIV clinic, I met with Dr David White, my consultant. He spoke to me about my hepatitis infections and their potential consequences.

456. This was the first time I was told openly about the long-term effects of HCV. He had explained that I needed close monitoring as if my infection persisted without treatment, I was at risk of developing cirrhosis of the liver, or liver cancer.

457. On 03 July 2000, Dr White became concerned as to whether I should be treated for my HCV. He wrote to the then Dr Mutimer, Hepatology Consultant at the QE Hospital, Birmingham, seeking advice as to the management of my HCV. He also wanted to explore the potential of a joint HIV/HCV clinic.

458. Dr Mutimer responded in a letter dated 18 July 2000 indicating that he was interested in establishing the joint clinic. The clinic was duly established.

459. On 22 January 2001, I saw Dr Mutimer and Dr M.J.Wood, consultant physician at Heartlands HIV unit. Due to this joint HIV/HCV clinic I was able to gain access to treatment for my HCV. My treatment commenced in

September 2001. Information surrounding my HCV treatment will be dealt with in my second statement.

Other Infections - Diagnosis of Hepatitis B ("HBV") Exhibit WITN4607028 refs.

460. In December 1983, when I was still a student at Treloar's, a blood test was requested by Dr.Strevens, Coventry and Warwickshire Haemophilia Centre, during the Christmas holidays. The blood test was carried out on 21 December 1983 and found to be Hepatitis B core antibody positive and surface antibody positive, but surface antigen negative.

461. This is confirmed in a laboratory report and a letter communicating the results to Dr.Strevens dated 19 January 1984, of which I have a copy.

462. Treloar's also performed a test on 10 January 1984 upon my return to college after the holiday. The result of that test also showed I was Hepatitis B Core and Hepatitis B surface Antibody positive. I also have a copy of this.

463. This was communicated to other medical professionals involved in my care, but it was never communicated to me. I only discovered this fact when reviewing my medical records five years later.

464. This is confirmed in a letter, dated 10 July 1984, from Dr M Wassef, Senior Clinical Medical Officer, Treloar Haemophilia Centre, Lord Mayor Treloar College, Basingstoke and North Hampshire Health Authority, to Dr Strevens, Coventry & Warwickshire Hospital. This letter has a relativity reference of **TREL0000335_109** (Exhibited below, as **WITN46070011)** it states:

"He remains HBs Ag negative. His Anti HBC and Anti HBs were positive on specimens taken on 10.1.84."

465. This had shown that I did not have an active HBV infection, but instead, I was Anti HBC and Anti HBs positive. Therefore, I was recovering from a previous HBV infection and I now had HBV antibodies, indicative of immunity.

466. This was around the same time that a number of the lads and I at Treloar's were told about the possible AIDS risks associated with the blood products we were receiving from America as treatment for our haemophilia.

467. I cannot pass comment as fact, at what point I was infected with HBV. However, upon inspection of my medical records, despite never exhibiting a recorded positive result for HBV antigen, which would have demonstrated an acute infection, I have found references that state I had been tested for the presence of Hepatitis A ("HAV") and HBV in January 1977 and was found to have tested negative.

468. Furthermore I was tested again for HBV antibodies at Birmingham Children's Hospital on 28 May 1979 and also demonstrated to be negative. However, by 21 December 1983, a positive test performed at Coventry and Warwickshire Hospital had demonstrated development of a HBV surface and core antibody.

469. Therefore, by process of elimination, the point of my HBV infection occurred between 28 May 1979 and 21 December 1983. During this period, I had received Autoplex and FEIBA during trials I took part in during the period 1980 to 1984 at Treloar's. I also received a single infusion of Hemofil Factor VIII on 11 January 1981 and I had also commenced the Bonn Protocol on 3 February 1983, whereby I was exposed to multiple units of Factor VIII. Additionally, I received several doses of Factor IX in another trial at Treloar's during 1983 and 1984.

470. After the doctors received my initial HBV diagnosis in December 1983, I was not told and did not receive any information about the infection, to allow me to adequately understand or manage my infection from Dr Wassef and Dr

Aronstam, nor from Professor Shinton and Dr. Strevens. I was also not told any information, about the risks of others being infected as a result of having had an HBV infection.

Other Infections - Diagnosis of Hepatitis A ("HAV") Exhibit WITN4607029 Refs.

471. When I was informed of my HCV diagnosis at Walsgrave Hospital in January 1993, I was also informed at that time that I had tested positive for antibodies to Hepatitis A. The nature of the result showed that I had developed an immunity following infection sometime previously.

472. I have copies of the laboratory reports relating to the tests undertaken on 18 January 1993 and 8 March 1993 that confirm my Hepatitis A infection and immunity.

473. I cannot pass comment as fact, at what point I was infected with HAV. However, upon inspection of my medical records, I have since found a note that states I had been tested for the presence of Hepatitis A ("HAV") and HBV in January 1977 and was found to have tested negative.

474. Therefore, by process of elimination, the point of my HAV infection occurred between January 1977 and January 1993.

475. During this period, both at Birmingham Children's Hospital and the John Radcliffe I received Factor VIII as treatment in June 1977, and I had received Autoplex and FEIBA during trials I took part in during the period 1980 to 1984 at Treloar's.

476. I also received a single infusion of Hemofil Factor VIII on 11 January 1981 and commenced the Bonn Protocol on 3 February 1983, completing it on 27 June 1984, whereby I was exposed to multiple units of Factor VIII.

477. I also received treatment with several doses of Factor IX during a trial at Treloar's in the period 1983 to 1984 and as treatment at Coventry and Warwickshire hospital in 1984.

478. I also received treatment with Whole Blood, FEIBA and Factor VIII at Coventry and Warwickshire Hospital/Walsgrave Hospital throughout the period; Substantial amounts of Factor VIII of various brands and batches were given as prophylaxis.

479. The blood products used variously became virally inactivated at different points during the mid1980's. It is therefore not possible for me to say in fact which treatment caused my infection, or at what point in this period.

480. This brings me to the end of the first part of my life as a child and a student at Treloars.

481. As previously stated, this is Part 1 of my statement. Notwithstanding a brief mention of the joint HIV/HCV clinic in 2000 the majority of this section of my life story deals with the time from birth up to early 1993 when I was 27 years old.

482. **My statement Part 2** will deal with the following: My deteriorating health condition. AIDS. The impact on my career, establishing a home and a purpose in life. The anti-viral treatments and their effects. Life in general, which will include, Illness, partial recovery, notification of vCJD, specialised treatments along with the HCV treatment and the care support I received. Financial Assistance. My campaigning to achieve acknowledgment and recognition. The need for those affected to be duly compensated. The need for a Public Inquiry.

Statement of Truth

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

Signed GRO-C

Dated 8 September 2021

Table of Exhibits:

Date	Notes/ Description	Exhibit number
19 May 1983	Letter from A Cameron, Scientific Officer, Travenol Laboratories Limited, to Dr A Aronstam, Director of Treloar Haemophilia Centre, entitled 'Autoplex Clinical Trial.' URN: **HHFT0001159_001**	**WITN4607002**
01 March 1983	Trial Protocol, entitled 'Clinical Evaluation of AutoplexR (Anti Inhibitor Coagulant Complex) in Inhibitor Patients,' as being a 'double blind single cross over study.' URN: **HHFT0001159_003**	**WITN4607003**
Undated	Flowchart, entitled 'Autoplex Clinical Trial: Instruction Flow Chart for Autoplex V Factor VIII Trial.'	**WITN4607004**

	URN: **HHFT0001159_002**	
September 1983	Handwritten Notes, entitled 'Autoplex Clinical Trial (Autoplex V F VIII Trial).' URN: **HHFT0001157**	**WITN4607005**
29 May 1982	Letter, from Dr F G H Hill, Consultant Haematologist, Birmingham Children's Hospital, to Dr A Aronstam, Consultant Haematologist, Treloar Haemophilia Centre, Lord Mayor Treloar College. URN: **TREL0000335_031**.	**WITN4607006**
27 March 1984	Letter, from Dr M Wassef, Senior Clinical Medical Officer, Treloar Haemophilia Centre, Lord Mayor Treloar College, Basingstoke and North Hampshire Health Authority, to Dr Strevens, Coventry and Warwickshire Hospital. URN: **TREL0000335_012**.	**WITN4607007**
06 April 1984	Letter, from M Wassef, Senior Clinical Medical Officer at the Treloar Haemophilia Centre, to Dr Strevens, Coventry and Warwickshire Hospital. URN: **TREL0000335_011**	**WITN4607008**
Undated	Graph, Showing Inhibitor levels in New Oxford Units, January 1983 to July 1984. URN: **TREL0000335_085**	**WITN4607009**

07 June 1984	Letter, from Dr M Wassef, Senior Clinical Medical Officer, Treloar Haemophilia Centre, Lord Mayor Treloar College, Basingstoke and North Hampshire Health Authority, to Dr M Strevens, Coventry and Warwickshire Hospital. URN: **TREL0000335_015**	**WITN4607010**
10 July 1984	Letter, from Dr M Wassef, Senior Clinical Medical Officer, Treloar Haemophilia Centre, Lord Mayor Treloar College, Basingstoke and North Hampshire Health Authority, to Dr Strevens, Coventry & Warwickshire Hospital. URN: **TREL0000335_109**	**WITN4607011**
29 June 1983	Letter, from Dr M Wassef, Senior Clinical Medical Officer, Treloar Haemophilia Centre, Lord Mayor Treloar College, Basingstoke and North Hampshire Health Authority, to Dr F G H Hill, Consultant Haematologist, Birmingham Children's Hospital, Birmingham). URN: **TREL0000335_020**	**WITN4607012**
1 February 1971	Inhibitor Development Documents	**WITN4607013**

April 1973	Spinal Bleed Documents	**WITN4607014**
03 Dec 1975	Letter from Dr Jillian R Mann to Dr GRO-D re Knee injury.	**WITN4607015**
1977	Head Injury documents	**WITN4607016**

1979	Lord Mayor Treloar College Admission letters	**WITN4607017**
1979-1984	Lord Mayor Treloar Parental Contact letters	**WITN4607018**
1983 -1984	Extracts form Lord Mayor Treloar Haemophilia Centre Records. Treloars Immune Tolerance Trial using high dose prophylaxis. (Note absence of trial information, consent.	**WITN4607019**

1980	Extracts from Lord Mayor Treloar Haemophilia Centre Records. Treloars Autoplex Trial 1980. Use on named patient basis or as a clinical trial. Note absence of trial information, objectives, protocols, formal consent.	**WITN4607020**
1981	Extracts from Lord Mayor Treloars Haemophilia Centre Records. Random uses of Factor VIII. Factor VIII "Hemofil" use January 1981.	**WITN4607021**
1981 - 1982	Extracts from Lord Mayor Treloar Haemophilia Centre Records. Apparent Treloars Trial of Porcine Factor VIII in 1981/2 Note absence of trial information, consent.	**WITN4607022**

1981	Extracts from Lord Mayor Treloar Haemophilia Centre Records. FEIBA Trial 1981.	**WITN4607023**
February 1983	Treloars Training Manual.	**WITN4607024**
1983 -1984	Extracts from Lord Mayor Treloar Haemophilia Centre. Factor IX Trial	**WITN4607025**

1983	Earliest Viral Awareness & HIV Diagnosis documentation.	**WITN4607026**
1991- 1993	Hepatitis C Investigation, Diagnosis 1991 & Notification 1993. Coventry & Warwickshire Hospital	**WITN4607027**
28-01-1977	Hepatitis B Investigations & Diagnosis	**WITN4607028**

18 Jan 1993	Hepatitis A Investigation, Diagnosis 1991 & Notification 1993.	**WITN4607029**
15 Oct 1985	Letter to Health & Safety Executive & Consent form dated 7 November 1985.	**WITN4607030**