

Witness Name: Adrian Paul Charles Goodyear

Statement No: WITN1243001

Exhibits:0

Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ADRIAN PAUL CHARLES GOODYEAR

I, Adrian Paul Charles Goodyear, will say as follows:-

Section 1. Introduction

1. My name is Adrian Paul Charles Goodyear. I was born on GRO-C 1971 and currently live at GRO-C Hampshire GRO-C I live in a small housing association house and I have resided here for nineteen years.
2. I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006.
3. This statement has been prepared without the benefit of access to my full medical records.

Section 2. How infected

4. I was co infected with HIV, Hepatitis B and Hepatitis C as a result of receiving contaminated Factor VIII which was administered as treatment for my severe haemophilia A. I was infected with Hepatitis B four times when I was 7, 9, 11 and 13 years old. I believe that my first Hepatitis B infection was from a Lister Factor VIII product in 1978. I believe that I was infected with HIV from heomophil Factor

VIII when I was 13 years old. I do not know when I became infected with non-A non-B Hepatitis (later called Hepatitis C), but I think it was at the same time that I was infected with HIV.

5. I was initially treated at St Mary's Hospital Portsmouth by Dr Peter Green. My haemophilia care then moved to Lord Mayor Treloar's School when I was 10 years old and was treated at the the Wessex Haemophilia Centre (which was part of Treloar's) by Dr Antony Aronstam and Dr Wassef amongst others. This Haemophilia Centre moved to Basingstoke in 1997. At around that time I transferred to St Thomas' Hospital for 10 months to obtain an HIV treatment Sequiniver, and then returned to Basingstoke where I was seen by several consultants throughout the years. Dr Sarah Mangles currently looks after my haemophilia care at the Uplands House Haemophilia Unit. Up until the age of 15 I also attended Worcester Hematology Centre during the summer holidays as we used to go there to stay with family.
6. I was born Adrian Paul Shaw. My mother, Kay Wade married Norman Wade and she had three sons from her first marriage all of whom suffered from severe Haemophilia A, called Gary, Jason and Paul. Paul died at just six months old due to feeding difficulties. My mother separated from her first husband and Gary and Jason stayed with their father. I lost contact with my step brother's until I was 18 years old. Gary and Jason were infected with contaminated blood products and Jason died from HIV / AIDS in 1997 and Gary died from a Hepatitis C related brain haemorrhage in December 2015.
7. After leaving her first husband my mother Kay moved to Portsmouth where she met my father, Frederick Shaw and I was born on GRO-C 1971. I was diagnosed with severe Haemophilia A when I was about six months old. Around this time my mother had a severe kidney disease which meant that her kidneys were not functioning properly and she could not cope and I was removed then from her care by the Local Authority.
8. I was subsequently fostered by the Goodyear family in Purbrook when I was just 6 months old. My foster family Bernard and Margaret Goodyear, unbeknown to

me, had a long standing history of short term fostering placements and in total fostered 42 children. Bernard had been in the navy and then involved with the ambulance service as a senior storekeeper and Margaret was a nurse. They had 5 children of their own who were all much older than me. Everything was okay until I was about 7 years old, before I was diagnosed with Hepatitis B. I was then adopted by them when I was 7 years old. I ended up be the only fostered child that they adopted and I believe that it was my father who pushed to adopt me. It took such a long time to adopt me as the Local Authority trying to place me back in the care of my birth mother Kay throughout that time, but she wasn't able to provide a suitable and stable home life due to her own ill health.

9. One of the reasons that I was placed with the Goodyear's was that **GRO-C** **GRO-C** had mild Von Willebrands disease and had been treated by Dr Green at St Mary's Hospital Portsmouth. My Dad had an unnerving feeling about Dr Green though, but when he started taking me to Dr Green on the ward during bleeding episodes, he began to trust him. However, from about the age of 4 my Dad informed me that Dr Green had said that in his professional opinion it would be best just to let the children with haemophilia go as it was a terrible condition to live with. Dr Green repeated this to my Dad several times over the years. My Dad certainly did not appreciate Dr Green saying all this about me due to his care and parental responsibilities towards me which he took very seriously.
10. I was infected with Hepatitis B in 1978 when I was 7, from the first ever batch of concentrate that I was given, which I believe was Lister. I was being treated for a frozen right ankle bleed at St Mary's Hospital in Portsmouth and was given UK sourced Factor VIII. My arm blistered more or less immediately after the injection and I turned yellow within the first 12 hours of receiving the Factor VIII. I also remember that when I was first infected with Hepatitis B, **GRO-D** a haematologist, gave me an extra shot in the middle of the night prior to my Dad taking me home the next morning. I never understood why, because I wasn't bleeding. I didn't require that dose and I was only ever in hospital with factor at the beginning of and during a bleeding episode.

11. Dad was in the Navy so he knew what Hepatitis looked like. When he saw me Dad became quite distressed and I saw him have an angry conversation with Dr Green. He questioned why I was fine when he dropped me off that morning at 7.30am but I was yellow when he came to see me at 6.30pm the same night. He asked Dr Green 'what have you done to my son, why does he look like that?', when he saw me turning all yellow and vomiting. He was simply told that Factor VIII was revolutionary so not to worry. Dr Green was so blasé, as far as arrogant even which further angered Dad. My dad was also told that "going yellow" was nothing to worry about as Dr Green went on to explain what was happening to me was "quite normal" that it would "eventually pass" and that it "would not come back". My Dad also told me later that Dr Green had again repeated his comments that it would be better to let haemophilia children go. My father felt powerless to help me after that episode and I don't know if he ever regained the confidence to do so. I also recall that he never wanted me in St Mary's Hospital again.

12. Subsequently, Dr Green then blocked my father from coming to the hospital for extended visiting hours due to him getting worked up and angry after seeing me in this condition after being in his care. After I contracted Hepatitis B my Dad was only allowed to see me for a brief time and during certain hours. Unlike other children who were allowed to have family stay sometimes right into the night. During the first period of the Hepatitis B infection, my family were not allowed to visit because of the hospital's infection protocols. However, I remember that other children on the ward were indeed allowed visitors, even in light of such protocols, and that I really was being treated quite differently to them.

13. My adoptive mother said that my father was never the same after that as he was concerned that there might be something in the blood products. Hepatitis B panicked my Dad and so he wanted to know everything about what was going on in the hospital so he could stay on top of things. If there was ever a problem he would always protect me. He often wanted to know about Dr Green and how I was being treated at every stage as Dad would be very careful and cautious about me. On one occasion, he took me out of hospital and took me home when

they wanted to keep me an extra 4 days due to such trust issues because as he saw it, the bleed had stopped and I was sitting there bored on the ward; he said there was no reason for me to stay.

14. After contracting Hepatitis B, on further hospital visits and admissions that my Dad couldn't attend, when I would come home, Dad would ask me what happened and whether Dr Green had done anything to me as Dad became even more protective of me. When I was about 8 my Dad told me about the conversation with Dr Green and asked me to try to remember anything in the future if I could.
15. I was infected with Hepatitis B again on two further occasions when I was aged 9 and 11. On each occasion I recall spending one or two weeks in isolation. At that time I was under the care of Dr Peter Green.
16. I was at Purbrook school from age 5 to 9 years old, where I was bullied on a daily basis. On my first day the headmaster pulled me in front of everyone in an assembly to explain that I could not be caned or hurt due to my haemophilia and I wasn't allowed to be hit by others so I was mostly bullied from the start of junior school life due to me being singled out in such a way. In the Easter term when I was 9 years old, another pupil, GRO-D smacked my elbow with an iron bar and fractured it as he wanted to see what happened when I bled. My Dad pulled me out of that school immediately and I never went back.
17. As far as I can ascertain, due to this extreme episode it was suggested to my parents that I could attend Lord Mayor Treloar's School and College in Hampshire which I attended from 1980 to 1989, but my Dad passed away in April 1980 prior to my starting there in the September of that year. He managed to take me to a tester open day in March but this was the last time I was with him properly. He died of a coronary a month later. I was subsequently blamed for his death. My Mum used to tell me that he wanted me and she did not and the stress I caused him eventually also caused his death. That was when the abuse really started. He was always worried about me and I think that she was envious of our relationship as she was a matriarchal and domineering type.

18. I began some home treatment, missing my own factor and so on when I was around 9 and I remember being worried by what was in the syringe which I attempted to address with my Mum; to my frustration Mum could never admit what happened in Portsmouth and often said "doctors cure people, not harm them". I was most confused by this as a child so this caused conflict between us and in my and her relationship with my Dad.
19. My parents could never really administer cryo or Factor very well at home, but I had my first home treatment-based Factor 8 infections at 9 and by the age of 10, I was almost ready to self-administer which I learned how to do at the Treloar haemophilia unit.
20. I started off at Treloar's in a plaster due to my fractured elbow and was in it for about a year, so most of my education was undertaken in the hospital in Portsmouth, at home or at Treloars. Every time I was released from hospital, I would go home for 2/3 days before having yet another bleed so needing to return to the hospital. Every time I had to go back for about 1/2 weeks to recover.
21. I was never given any information and nor were my parents, regarding any of my infections, nor of the risks to me from blood products. My Dad would have said 'no' to me being administered the then newer concentrated treatments if there had been any risks that he was made aware of but, he wasn't. Dad came to my appointments as my mum couldn't drive. However, my mum came to some appointments when she could.
22. My first memories of attending Treloar School are of beautiful rolling countryside, with far reaching views across the vast open space for mile upon mile overlooked by an awe-inspiring Jacobean mansion, alongside a medieval church and spread over a vast thirty-seven-acre site. It was a wonderful place for a ten-year-old sheltered but inquisitive child to be a child as junior school at home didn't work out for me. There were many pupils in wheelchairs as well as those who could walk and talk with varying degrees of ability and disability across the broad spectrum that a specialist school such as this encompasses. That was an education but as children, you don't judge, you simply accept the world around you and make your bonds and friends spontaneously.

23. Due to severe haemophilia type A, I missed much schooling as I was in hospital for extended periods with numerous painful internal bleeding episodes into my joints and muscles. Also, the 'care' at my original haemophilia centre at St Mary's hospital in Portsmouth was appalling throughout the 1970s, due to a lack of understanding about the condition, so it was suggested that I attend L.M.T.C in hope that I would receive some form of education - which I did on all levels.
24. There were many people with haemophilia at the school and college which was split over two campuses and built on the foundations of a private boarding school, with all the traditions of such institutions firmly intact. Its long history was first set down by the esteemed Sir William Purdie Treloar, a former Lord Mayor of London who formed The Treloar Trust in 1907 - prestigious and superior beginnings indeed and there was an air of that importance of achievement that graced the establishment with much focus on education and independence regardless of any personal limitations that many of us had.
25. The juniors, aged 8-15, attended the lower school in Froyle and those 16+ the upper school three miles away in Holybourne, Hampshire where the Treloar haemophilia centre was situated. There was always a wide range of support and advice available to us and our peers via the vast array of on-site staff; nurses, physios, teachers and assistants who were dedicated to us pupils. It was a vibrant place in the main and all our educational and medical requirements were all in-house so to speak.
26. Being with other haemophiliacs was a good thing especially being away from our families during the long ten to twelve-week school terms. We would support each other, and heartfelt friendships were formed based on our youthful understanding of the condition. There were two other haemophiliacs in my first dormitory who were **GRO-C** and Chris Piggott. From the experienced elder's right down to the youngest, we shared daily treatment appointments under the guidance of the late Dr A. Aronstam who was with us at nearly every clinic most mornings and ran an open-door policy at the NHS funded unit. We also had our own transfusion room, along with its own lab which we shared sometimes twice a day

for the said treatments. We were a solid bunch and it was a completely unique and immersive school experience, if not a little daunting being away from our families at such tender ages that boarding school life provides.

27. We shared dormitories, fell in, fell out, fell over, did school, understood bleeds and began training in how to self-infuse Factor 8 and Factor 9 around aged ten, which was a Godsend and of course all the other normal kid's stuff was in full flow. Regular trips out and even abroad, every conceivable club you could want to be a part of from chess, sailing, music, drama, sports and activities. Royal visits, pop stars, celebrities and known faces of the day were regular visitors to the school, it was inspiring. Strong bonds were made beyond what we could ever hope for in our home lives which sometimes drove wedges between us boys and our families, but we were encouraged to phone and write home weekly to sustain those relationships.

28. One of our much loved Haemophilia nurses, Annie Kelly, dubbed us her 'Golden Boys' as the plasma was a bit yellow when it went in and just in case we went yellow, as they knew all about hepatitis. We often looked to be the healthiest bunch at the school, but if only we knew what was lying in wait for us.

29. I was told later by Charles Loader, who was a pupil of Treloar's in the 1970s but has since passed away, that in 1980 Dr Aronstam attended a Hematologist conference in South America discussing heat treatment and product safety where he expressed his concerns about the need to heat treat the Factor concentrate. At this conference, Dr Aronstam introduced two German experts from Behringwerke, who gave a presentation to the conference advising their company could Heat Treat Factor VIII. Dr Aronstam thought that it was possible to get heat treated blood products in after testing and within 3 months of the 1980 conference. I cannot find any documentation regarding this international haemophilia conference and I also believe that the factor heating part of Behringwerke was later was bought out by an American company.

30. I remember a conversation with Dr Aronstam in or around 1991 when I went in for a regular treatment for an elbow bleed at the Haemophilia Centre one

evening. Dr Aronstam was quite exasperated and rather agitated. He explained to me that the PHLS had 'f***** him'. He said that he had done all he could and that he had done his best but did not understand why they did not listen to him and implement heat treated blood products when he suggested they do so. He believed that by 1981 or 1982 we would have all been on heat treated products and with this, he said that AIDS/HIV did not need to happen.

31. Dr Aronstam attempted to do his own heat treatment on the Treloar centre Factor from 1982. In the transfusion room there was a mixing machine. He consistently checked the water temperature and so did the staff for it to not fall below 28 degrees. They also would not let the factor out of the machine below the minimum of 20 to 25 minutes reconstitution time. Speculatively he and the other staff must have been attempting their own heat-treatment, which he may have thought was the maximum time before plasma may spoil under certain temperatures. Sadly, it was all too little, too late. Additionally, at home on the school holidays, I remember having to place some warm water in bowl to make sure the Factor concentrate stayed at 28 degrees while mixing it and having to check this process with a thermometer provided by the Treloar centre, after it left the family fridge. Back at school, Dr Aronstam or Dr Wassef would sometimes say *"don't worry boys we're going to warm it up. There will be no more yellow (hepatitis)"*. I also have a copy of Treloar's home training programme from 1981; the home treatment plan for Factor concentrate administration which I started as did all its haemophiliac students from aged 10 at the school.

32. In or around September 1982 Dr Aronstam chose 50 Treloar's boys for an 8-month trial with American Plasma from Spayware Laboratories. This was at the height of the AIDS crisis. I believe I was given haemophil in a non-branded bottle, which I believe to have been manufactured by either Alpha or Cutter laboratories. I do not, to this day, understand why Dr Aronstam was involved with such a risky trial in 1982 with US blood plasma for concentrate and its subsequent administration, especially after attending the 1980 conference regarding his then commitment to heat-treatment and safer supplies for us. Why the change of tac? It was and thus remains the polar-opposite of who Dr Aronstam was as a doctor and who I thought as a person. This has created such a perplexing tear in the

timeline of my knowledge base. I do not know if it was wilful blindness or whether was being guided at the time to undertake such project with us children and young teens without due regard for our medical wellbeing. I believe that every boy on the trial at Treloar's got HIV.

33. We didn't attend the school to be tested on without our or our guardians' consent in trials, we were simply there to learn. Also, during the trial there didn't appear to be a shortage of either Scottish or English Factor VIII or IX for that matter. They had 3 fridges and on the top shelf was the Scottish Factor VIII (as this was deemed the safest) then the English Factor VIII on the next shelf down and, at the bottom, the American Factor VIII. We had previously been told to start at the top with the Scottish Factor VIII. Yvonne Stebbings, who became a haemophilia nurse whilst at the college, explained to some of us that it was 'one batch' that infected us with HIV at Treloars. Given the above I believe the Spaywood 'haemofil' plasma to be the missing link in how I contracted the virus at the school.

34. From around September 1982, after returning from the eight-week summer holiday, there was a new product on the transfusion room table. It stood out as it was different to other factor bottles due to its basic white label on the bottles. I came out in rashes and had several bad reactions to those factor treatments. I believe this is when I was infected and sero-converted with HIV.

35. Over the Christmas Holidays in 1982, the Treloar/Wessex Haemophilia Centre was refurbished and extended considerably building wise at the back of the medical centre at Treloar College. When we came back at the start of the 1983 spring term, it appeared that a new dawn in haemophilia treatment had been built. I do not know where the funding for this work came from. Especially being a separate DoH funded entity from the school itself and independent of The Treloar Trust i.e. the school's charitable arm but, in any event, Treloars would have had to have given permission for its own private school land to be used/rented/purchased for the purpose of the extension of the centre. The Inquiry should look into which body provided the relevant funding for such an undertaking to take place. There was a new consultation room, a communal room and two new offices, one secretarial and one for

doctors. It also had its own mini-lab and a new isolation wing adjacent to the centre at situated in the Treloar Medical centre. Given this I think it a prudent question to ask who funded this venture before and/or around the time of the trial of U.S supplied plasma that Dr Aronstam assisted in providing fifty of us boys for?

36. There was a moment in 1983 when I and my friend Simon, who died in 1999, were in the haemophilia clinic at a lunchtime clinic. I remember that Dr Aronstam walked two American pharmaceutical representatives out of the Centre, robustly informing them *"don't come selling your s*** to us again"*. I had never heard Dr Aronstam swear before. I remember the sharp suits, cufflinks, watches and Beamers of those Americans.
37. The happy memories are layered with a sadness that still gives the goose bumps today though. In the early 1980s some of us started becoming unwell and developed jaundice after being infected with various strains of the Hepatitis virus. I had already been infected with Hepatitis B a few years previously at my Centre in Portsmouth aged just seven. History had repeated itself for the masses and at the school many were quite unwell. But we did not have full understanding of why, but with the childhood of youth on side; we seemed to get through somehow.
38. I remember around May 1983 a member of staff had left a Daily Mail newspaper with the article 'Killer Blood' In the TV room which we read. We were not allowed access to newspapers at the time given our age and I have since been informed, that Treloar's terminated the employment of the staff member who left that paper in the television room at that time.
39. Within the first week of the summer holidays in 1983 I ended up extremely poorly. It started with a dreadful and debilitating ear ache and a gland behind my left ear that became rather enlarged. My eyes became yellow, every gland went up, and I had vomiting and diarrhoea and a many spikes in temperature with sweats. These were the first signs that something was not right. I could not go to Worcester with the family as normal for the first week of the summer holidays

and only went the week later. My mum and aunt were very worried about me and I was unwell during the whole of the holiday.

40. After that holiday, when I got back and went back to Treloar's in September 1983, there was a note on my bed telling me that I had to go to the sick bay. I do not know how they knew I had been unwell over the holidays though. I was kept in isolation with barrier nursing for 2/3 weeks, and then told I had Hepatitis again.

41. My mum phoned me during the second week because she had not heard from me (as was normal practice for us to ring home every week). I had not been told about Hepatitis at this point, but I knew they were looking out for it because of the tests they were carrying out on me. I just told her that I had gone yellow again. I remember thinking, why am I in isolation and not in hospital.

42. From memory, in 1983, we had a friend called Richard who became very pale, gaunt, had lost a lot of weight and became rather withdrawn; this just wasn't like him at all. I instinctively remember thinking 'something's very wrong'. You don't really die of haemophilia in that way but that is precisely what happened. One day he was there, the next week he had gone. He was a good dorm mate and was popular. He would have been around thirteen at the time and he just didn't come back after half term I think around October 1983. On our return to school for the run up to Christmas that year, his passing was read out the usual Treloar way at an assembly and naturally, a group of us started asking about what had happened and why. We were informed there may be something like a virus in the factor, but we were not to worry until more information was known and, that we would be looked after. We had no reason to doubt this at the time as we were young, but little did we know that his immune system had just crashed. It later transpired that he had been the first college pupil to tragically die of HIV/AIDS.

43. I believe that Treloar's was a 'gift' of an establishment for pharmaceutical companies to try out their products whilst knowing little boys and young adults were being maimed and harmed on mass. The pharmaceutical companies left gifts, which the staff would give to us as incentives to take treatments and likewise when we behaved. It was positive reinforcement. We were even offered branded gifts such as chronograph watches, pyramid clocks, stationary kits

(Bayer Filofax and pens), back packs and so on all branded with certain pharmaceutical company logos, mainly American. Looking back now, it was like being groomed by the 'peddlers of death' but at the time we were happy with the set up as it they were freebies.

44. There was a drive for prophylaxis from the beginning and for immune tolerance therapy for the boys with inhibitors. Nobody wanted to be on prophylaxis; firstly, because it meant being tied to the transfusion room being jabbed' after breakfast daily, or on alternate days and secondly, because people were becoming worried about the treatment. Us boys had overheard conversations about the factor and our livers between ourselves, let alone the doctors.

45. I was given a lot of Factor VIII at Treloar's. If you had a bad bleed at night you would be given Factor VIII injections twice – once that night and another one the following morning even though, knowing what I know now, I am sure that one would have done.

46. My family were concerned though; especially my sister Elisabeth, as she was a nurse, as press from the United States began trickling through that haemophiliacs had began dying from a mystery illness. Many were doing their best to protect us from such knowledge due to our tender age and as it transpired it became nigh on impossible to stop what was going on. Even Dr Aronstam in his many endeavors couldn't. He was very much a hero to us haemo boys and he attempted to stand against the powers that governed the medical profession at the time. An old school doctor and family man whose note-keeping was impeccable as was his right-hand man and colleague Dr M. Wassef, who we had the most dealings with at the centre and socially around the school as he and his wife lived on site. With so many patients in one place, around fifty or so, what do you do when a haemophiliac has a frozen joint bleed at 2am? Cryoprecipitate had been phased out due to continuing pressure from the UKHCDO to make way for these revolutionary new treatments and due to such policies, mostly American, British and Scottish blood concentrate products were filling the fridges by this time. Factor concentrates were in abundance. Even 8Y, the preferred choice chosen to treat us over anything remotely American

(especially in the pre-heated treatment days due to it being a British plasma derived concentrate), turned out was loaded with Hepatitis. It was all so helpless.

47. In the summer of 1984, Dr Aronstam invited my friend [GRO-C] and I to his house. We had a great day with him and his wife by the swimming pool. It sticks in my mind because at one stage, after he had brought out tea and lemonade, he said *"that's it, we really have, we probably have really f***ed up."* There was an immediate change in the atmosphere. I didn't know why at the time, but I now believe that he knew, at that point, that the factor products were infected and that it was likely boys were infected with HIV. [GRO-C] was braver than me and said to him *"are we ok Dr Aronstam?"* He replied, *"we're doing our best"* and said something about stormy weather and the road ahead. [GRO-C] didn't let it go and asked again, *"are we sick?"* Dr Aronstam wouldn't give a straight answer, but tears embraced his eyes and he softly said *"I'll be there; we'll be there for you."*

48. Around 1984 I believe that Dr Aronstam, Dr Winter at Margate and Dr Savage at St Thomas's all purchased heat-treated products early and that this saved some lives.

49. I remember the day we were told of our HIV statuses in or around May 1985. I was only fifteen years old. It was late morning and we went into the office in groups of five. It was a surreal but relaxed atmosphere as the staff wanted us to maintain our kinships and keep the camaraderie up via the open-door policy we were used to by now. They talked to us about hepatitis B and non-A and Non-B and other viruses such as CMV and Parvo virus that had contaminated the supplies. They explained that CMV is an immune disorder that lies behind the eyes and is only active when T-cells are suppressed. We were told that we all had CMV whereas it is normally only apparent in 40% of the general population. They even light heartedly joked that Parvo virus is normally only found in dogs but there is a human form, as if to try to lighten the mood.

50. Dr Aronstam and his team, which included Dr Wassef, our head of physiotherapy Joyce Lovering and two haemophilia nurses Ann Hess and I think Jane Cartilage (now Price) cautiously informed us that *'you may have heard that Factor VIII isn't*

as clean as it should be'. Believe it or not we all knew what was coming from newspaper reports and conversations between ourselves and our hearts were in our boots. Whilst going slowly around the room Dr Aronstam told us who had HIV by the words *'you haven't, you have, you have, you haven't'* and so on. I was the last one to be told.

51. One of the boys, GRO-C asked, *'How long have we got?'* and I immediately repeated the question and the nurses welled up. *'As we know very little about HIV we honestly can't say but we think at this time around two to three years but maybe more'*. It felt surreal. The doctors then went on to explain that it was something to do with T-cells. They hoped it was an antibody and we would have a resistance to it. Not long after we were taught how to draw T-cell and B-cells. We more or less became mini scientists as this was another example of the expert teaching that the center provided. They wanted us to understand as much as we could absorb. This approach was a regular Treloar thing in hope we could achieve as much understanding as possible.

52. We were told not to tell anyone at school about our viral statuses as they did not want any more press interest at the school as there had already been as such. It was a huge strain and drove a wedge between me and some other friends and in other peer groups who were not infected with HIV, but who had contracted Hepatitis B and C. It was a frightening time and some of the haemophiliac boys were fighting because everyone was scared. We did not know how to react as suddenly we were going to die, and we have a sexually transmitted disease. The newspapers at the time described it as the gay plague.

53. We were sick and the world changed in a click for all of us that day, in that room, and then soon the next group was going in. Calm aligned with shock and confusion, yes, absolute confusion like a spinning top out of control. Walking out into the sunshine, after leaving the office, a numbness took hold as the sun was beating through the blinds. I remember looking at the sun and thought, how many more days will I be seeing the sunshine for? Another friend said *'I think we're dead. we're f*****g dead!'* before heading to the Horticulture department immediately next door to the centre and smashing a few potting shed windows in sheer anger at the situation. Personally, after the meeting, I was actually back in

science that afternoon, that's madness to me today. Today I'm the only remaining survivor in my group of five still 'blessed' to be alive.

54. The school then enforced the six-inch rule, which meant that you were not allowed to touch someone within 6 inches of your body within school hours. There was a teacher who would approach us with a ruler or tape measure, even at break time, to see how close you were to your friends. The six-inch rule had always been part of the college rulebook but, it was now being initiated around the clock by some staff members in a now obvious damage limitation exercise.

55. Another teacher, **GRO-D** who was a careers adviser and I/we all thought was a bully, kept trying to find out which pupils were infected. She called in every haemophiliac to see her to try to find out who had HIV, whilst I believe disguising this as 'careers advice', in a way to find out who had contracted it. I didn't tell her anything. A friend Ray Mitchell, who has since passed away and I, told **GRO-D** that she was obsessed with it. Dr Aronstam told us to inform him if anyone ever asked about our HIV statuses. He would speak to the teachers who would ask and tell them not to. That was for our protection at the time.

56. Dr Aronstam always stated that this happened on his watch and so he used to take extra care over us and look out for us. He always used to say "my watch" and never "our watch". He felt guilty.

57. I fell out further with my mum because I didn't want to go out because of the taunts. My mum didn't appreciate this. When I had told my mum about my infections, she went and told everyone on our home street that I was infected. This was around 1985. I do not understand why she did this, but I believe that she had an attention seeking disorder of some description. Mum said she just didn't want me around anymore and that 'only my Dad had wanted to adopt me', but he had died already. Mum was already telling everyone of my infected status far before I told her anyway and before any tests had even been performed on me or anything had been confirmed. It was almost as if she was wishing it on me so she could reject me further to which she did a year or so later.

58. When I went home for leave weekends, half terms and the school holidays, I was taunted with daily chants of "*hey Ade, you got AIDS yet*" and "*Live AIDS coming*" which was a pun on my name 'Ade'. Others shouted at Mum "*we know what your sons got*", G.A.Y – Got Aids Yet? which brought shame on the family. I didn't know what to do; I was so isolated and alone that it was heart breaking if it was happening to another, let alone it happening to me. I could no longer go out in the surrounding areas of Portsmouth. It was relentless but I kept that a secret due to embarrassment. People of my age range and certain home life friends stopped visiting too. The newspapers were full of haemophiliacs, viruses, haemophiliacs, viruses and so it went on. You didn't dare use the word haemophilia outside of Treloar's because of this.

59. I was told I had got HIV when I was 15 years old in May 1985. Mum didn't or chose to not believe me. My medical notes record that my mother was not given my formal diagnosis until I was 16 years old and, but she still did not believe me even when I told her. It was all very confusing but the delay in her being officially informed of my infection/s, played a large part in being detrimental to what was already an abusive and impossible relationship. Further to which, she phoned the Haemophilia Society back in 1984 to inquire if my treatment was safe, they went onto explain it was and I/we were to carry on as usual to which she naturally found reassuring. But this literally added toward further unhealthy and inappropriate conflicts because we knew by now the clear risks and knowledge that HIV was in the Factor VIII. The Haemophilia Society, someone or anyone should been more pro-active and transparent from the offset on top of which, the Treloars centre should have picked up a phone, communicated in some way the genuine truth of what was going on with their haemophilia students and charges but instead, chose to hide behind the school gates. Hindsight is not an excuse here and really, how can it be? So, given this, there was an inextricable wedge between myself and my mum that was destined never to be repaired or even healed. HIV just exasperated and magnified everything on top of being a teenager and it and was the end of the line for us both. We were bad, I felt bad, everything was bad, and the situation was dire. We simply couldn't maintain any kind of 'normal' life as it had been far from such and we splintered apart. In truth, looking back, I can now see why.

60. Following my diagnosis our relationship broke down entirely. Around Easter 1986 my mum physically attacked me with a 2-litre coke bottle as "I had brought shame on her". In self defence I pushed her back as I didn't want a head bleed as I felt myself starting to black out. I was returned into care by Court Order and placed at Kerr House children's' home in Cosham in the summer of 1986. After this incident I went back to where I started, in the care home in Portsmouth for 10 months.
61. I left the care home after about 10 months as two members of staff at Treloar's, Pat Salt and Maureen Leary agreed to look after me and let me stay with them in the school holidays. They normalized my life and as a result I did better in my studies. I see them as my surrogate guardians and am still in close contact with them.
62. After my mum was told herself of HIV by Treloar's in or around November 1986 she told them that her relationship with me had broken down because they didn't tell her about the infection. She therefore blamed them for our relationship breaking down also.
63. While I kept in touch with my five brothers and sister I did not speak to my mum until around 1991, when she asked me why I had not told her that I had HIV, but I had. She passed away two years ago.
64. When it became clear that we were infected Dr Aronstam took a step back and we hardly saw him compared to such times before but, he was often at conferences and meetings away from the center but as to the nature of what they were I'm not sure. He was always learning.
65. It transpired that many lived for longer but the struggles with our immune systems were immense as our cell counts slowly depleted. Cold sore after sore, shingles, glandular fever, fatigue, diminishing platelet counts which in haemophilia meant severe and advanced bruising, night sweat after sweat, fever after fever, more jaundice and weight loss. Pneumonia, severe depressions, none of which kids would get naturally, that list goes on.

66. The Haemophilia Centre at the college was a part of the Treloar's site but was very much seen at the time by the 'big smoke' centres such as Oxford, St Thomas's and The Royal Free as just a rural centre with little to offer in the way of ground-breaking treatment protocols. It was grass roots Haemophilia care of the highest standard for its day, but was never taken seriously enough which, I have since learned, often frustrated Dr Aronstam and he did have an ego, especially given the fact that he went for the Haemophilia Centre director's post at St Thomas's in 1979 but he didn't get the position, instead landing the post as the Treloar centre director instead. This may have had something to do with the fact that he wanted to play no part in the 'virgin haemophilia pup (Previously Untreated Patients) program being suggested by other professionals which would have led to further exposing 'virgin haemophiliacs' to blood borne infections alongside other ludicrous ideas of the day. Even in light of the horror that was unfolding, the safety of his patients was in conflict regarding the fallout of all that lay ahead for of us all.

67. There are still many missing links and unanswered questions as to why concentrate therapy was still being administered so regularly in the light of such a desperate scenario. That said, we still had haemophilia. It needed to be treated and we were already multiply infected with every single virus that factor concentrates had to offer. Everyone an unquantifiable social pariah because of those bottles as joint damage prevention from repeated bleeds was still a key. Nurses struggled with how to tell parents who didn't know how to cope as falling tombstones around 1987 were telling us 'not to die of ignorance' while our mortalities were played out in state funded commercials regarding AIDS as family after family across the country became terrified of how this virus could be transmitted. The guilt that many parents felt was and is simply immeasurable as Haemophilia is genetic. It was lock down on every emotional, physical and psychological level in every kind of relationship and we were just kids. We still had to finish our studies, which was for many an arduous or near impossible task.

68. By the early 1990's morale was at an all time low. Everyone was pretty much burnt out after being on the frontline for so long. Those who'd remained in the Alton area and other patients who used the centre in an outpatient capacity were hit with seven deaths (five Treloar's boys and two outpatients) from AIDS and Hepatitis in the winter of 1992 alone. They just never came back to the poly-gym physio and swimming sessions that the Haemophilia Centre provided after the holidays.
69. Everything had dissipated into a plague-like, disease-ridden mush for all parties as the prolonged pain of living with such devastation had ravaged everyone in its wake. For those of us who had out-lived that two to three-year time frame still faced yet further fear as the test became available for Hepatitis C a year previously with a 99% hit rate. It was all so very desperate and above all sad. To date seventy-three Trelorians are have known to have died from their infections.
70. Earlier on I mentioned a nurse called Annie who nicknamed us her Golden Boys'. She was simply the most amazing nurse. Her dedication to our care was so compassionate and no matter how much pain we were in, we always knew she'd get us better because she had the 'magic juice'. Annie never missed a vein when giving any treatments and with every internal bleed, of which there were hundreds between us, she had a way of reducing pain just by her calm and kind approach. She was every inch what you'd imagine a great nurse to be and a true heroine to me and her many other patients. Due to crippling rheumatoid arthritis in her hands and many of her key joints, she had to take early retirement in 1985 and in doing so left a legacy of superb care behind her.
71. In the mid-1990s I met a lovely lady named Mary who knew of my condition and knew Annie well after they met at a local church. I was surprised but equally elated as it would of course be lovely to see Annie again but when I asked after her Mary welled up. She went onto explain that she had become quite reclusive; in part due to her arthritis but also because she felt personally responsible for infecting maybe hundreds of patients in her care. I made sure that Mary took my

contact details and got a message to Annie that I would love to see her again if she'd like and of course to try to put her mind at rest.

72. This came to fruition and just a few days later there I was in a small flat with the very lady who made having Haemophilia, well, safer, to be honest. Holding her gently in greeting she began to cry saying "I'm so sorry; you boys know that don't you?" I kept on reassuring her but there were so many apologies falling from her lips that the guilt this beautiful lady had been living and feeling with was incomprehensible. She truly believed that she was responsible for the pain and suffering caused by contaminated blood and it had eaten away at her for all these years and in her words 'through the treatment she'd given us'. She repeated several times that she really didn't know, and I knew in my heart she didn't but nor did I ever think she did.

73. Our lovely Annie was just doing her job and quite brilliantly. I made sure she knew how fantastic all 'her boys' thought she was and still did. I spent the whole afternoon with her going through an array of mixed emotions over what happened, and we got to a point where we were thankfully laughing about old times. On leaving her flat that day I hoped in some way I'd been able to put her mind at rest and I went on to see Annie fairly often after that. I made sure she got out on her mobility scooter and helped her feel more at ease with what happened to 'her boys' but some six weeks later Annie passed away. I wasn't the only one who visited her of course as many of her colleagues were in constant contact but in looking back, I seemed to be a missing link in a chain of events and I hoped she'd passed healed in some way because one her boys had visited her. Mary confirmed that she'd been able to turn her feelings of guilt around and thankfully died at peace, if only I'd have got there sooner but at least I got there.

74. At Treloar's there was a small unit with a lab, two small consultation rooms and transfusion rooms all of which became home. The factor products were stored in fridges and always in this order: Scottish at the top (which was deemed to be the best quality), English in the middle and the American product at the bottom. We were told that they tried not to use the American product because it was best to "buy British".

75. In around 1991, around the time of the HIV litigation when we were asked to sign waivers for the settlement, Dr Aronstam explained to me privately that he felt as if he had been stitched up by the Department of Health, the PHLS and some of his colleagues. He said that in the 1970s and 1980s he was perceived by the Department of Health and other haemophilia centre directors as standing in the way of progress towards better treatment for haemophiliacs.
76. There was another close friend, Chris Piggott, who had Von Willebrands Disease and with whom we also shared a dormitory with for three years. He had only ever had three factor injections in his life and the all-American products at Treloar's sufficed as he didn't really need Factor VIII transfusions but, he did suffer with regular and heavy nose bleeds. On one of these occasions (when me and another haemophilia friend Simon, now also deceased) were present in the transfusion room, he had 'one of his noses' so, it was thought that Factor might help slow the flow. Sadly, one of if not all three of those injections were loaded with HIV. Chris died only six years later on 23 November 1991, aged 20 from AIDS. We had heard that his family had to say he passed from cancer due to the stigma that surrounded haemophilia and AIDS and it beggars belief, that to this very day, such families are still having to hide the facts about what their children and loved ones truly died from, due to the stigma surrounding HIV at that time, which in many ways continues to this day. There are so, so many stories like this serving the ravages of so much disease that came to be injected into us over and over again in a perpetual toxic and viral soup as mere children. We were simply too young live but equally destined to die.
77. I do not feel that we should have been told of HIV infection earlier as I think we were told as soon as it was known but the warnings should have been clearer and age defined/appropriate.
78. I am happy with how they explained it to me on 1985 in a group of 5 boys as it fitted in with the context and what it was like at Treloar's at the time, but the then doctors should have phoned my mother and told her so I am not happy with that, and am in fact angry that they did not tell her until 1986 as history now dictates.

79. I was told about the risks of infecting others sexually and they explained the risks of infecting others through blood and other bodily fluids. I think they told us as much as they knew and what was known at the time.

80. I was infected with Non A Non B Hepatitis (subsequently called Hepatitis C) in 1983 whilst at the Wessex Haemophilia Centre based at the Lord Mayor Treloar's School and College, Alton, under the care of Dr Anthony Aronstam. I did not find out about the infection until September 1991 when I was 20, some 8 years after I was infected. I was told by Dr Wassef in a regular appointment. He said that in 1988 there was a beta test for non A non B Hepatitis which showed I was positive, but they did not tell me of this result at the time but they were aware of its presence in the Non A, Non B sense.

81. I was not given any information regarding Hepatitis C at all. It was a non-event by this point. Everything I experienced medically was solely focused on HIV/Aids whilst still maintaining and providing treatment for my haemophilia.

Section 3. Other Infections

82. I believe I have been exposed to CMV, Hepatitis (A to G), Parvo and a host of other pathogens.

83. I am at risk of vCJD but this is down played in Parliamentary debates in a similar way to Hepatitis B. Today surgeons still wait until the end of the day to carry out procedures on anyone at risk of vCJD; they then have to dispose of expensive equipment after surgery. This was detrimental to my care as I waited five years for my ankles to be 'repaired'. Another reminder of our lifelong infections due to Factor 8.

Section 4. Consent

84. We were tested and treated without our knowledge or consent, but as soon as we were tested, we were told of results (in respect of HIV).

85. I believe that I was tested and treated without adequate information.

86. I believe that I was treated and tested for the purposes of research without my consent. They used to take extra blood from us about every three months and when I once asked why this was, I was told it was for haemophilia research or genetics. I know they were sent to Oxford because once one slipped out of the bag labelled Oxford. Sometimes it was even couriered. Looking back now this does seem odd but I think that they were keeping an eye on our T—cells as they knew we had HIV. Also, they often said they had lost our blood vials so that they needed to take it again.

Section 5. Impact of the Infection

87. At Basingstoke hospital in September 1986, an influential Haematologist said directly to me, "Adrian, do you know how lucky you are to be alive and have free treatment for your Haemophilia?"

88. Now that hurt. I felt punished for even having haemophilia in the first place after that and that's never really left me. That cut so deep especially after being diagnosed just a year earlier with HIV. Looking for some solace and security in the early stages of teenage life, I tried to discuss this with my Mum and to my disbelief she actually agreed with the doctor! Her words sounded heartless to my innocent and naive ears and it was given my diagnosis.

89. I was brought up with a crystal-clear sense of other people's situations and often reminded how many other kids round the world don't have adequate treatment for their Haemophilia and how fortunate I was that I did. So there it was; the common thread. The same viewpoints that bound together that doctor and my Mother. Two very influential people who, in my youth, became polar opposites of what was happening to me. It was very confusing, and I became trapped in a 'who cares now?' syndrome.

90. All I knew was I'd been given a death sentence 'for free' and what, I should be thankful for that? The malice implied by that doctor's comments came with no shame. She was too arrogant to deliver a fundamental part of the

doctor/patient relationship; trust. From that day forward any trust in my treatment for Haemophilia was inexplicably damaged, compounded beyond repair. To define my thoughts on leaving the hospital that day, it dawned on me that I'd become a walking virus, a disease to be ashamed of and I knew I was in some real trouble. This virus would define me, judge me and I will continually be judged for it. This fear continues to this day.

91. In fairness Mums reactions do make some sense now though. What kind of advice can a Mother give when the fear of the unknown is taking precedence over everything else? The senseless situation was just that; senseless, but the gravity immense, as life was unravelling itself from everything we both knew and there was no-one to put it back into some sort of order.

92. Dying from haemophilia was always a risk, yes, but dying because of the very treatment given for it "No", and given by the very people whose job it was to do so, the 'lifesavers' was near impossible for any of us quantify. Adult decisions and reactions forcibly placed at my feet, today that would be deemed as some form of child abuse.

93. It was a catch 22 situation for me and all of us severe haemophiliacs that required concentrate therapy. A Russian Roulette cliché but undeniably true. I was bright enough even at the age of 12 to realise that the Factor was bound to be infected with other viruses too so it was always in the ether. It was and still is down to the impossible position we've been placed in through NHS supplied contaminated factor.

94. It was clear from the offset that afternoon that haemophiliacs were in the way. We were always difficult to treat but now we'd become the untreatable, a death sentence in her consultation room that served as a constant reminder that conflicts with the ethics of being a doctor, saving lives and not maiming them. And above all I was hurt, really hurt by the prospect of dying by just 17 as I hadn't lived yet. I hadn't had time to notice the broken bottles on the beach but suddenly I was becoming just that...broken

95. My school work had suffered profoundly even though I was a bright student prior to all that was going on. I became difficult to live with because I was so scared of dying and worried how my other friends with Haemophilia from my centre might die as we were a close-knit bunch. I still can't believe that I've lost so many friends and family due to Aids and Hepatitis and not a day goes by where I don't think of them.
96. I felt like a disease because I was diseased and all we could hear and see was AIDS. My haemophiliac friends were becoming sick and dying young and so horribly, and we were all constantly living in the shadow of it. I just didn't know who or where to turn to. I couldn't turn to home because of the usual teenage conflicts and the added pressure of the circumstances. I used to have a deep awareness of God in life but how could God do this? I couldn't confide in Doctors because they'd become the centre of my fear, highlighted by every syringe of Factor (sometimes 9 a week). I couldn't confide in my friends because what I had would only get in the way of their own teenage dreams; the dreams that I thought I wouldn't be a part of because I'd be gone.
97. I was making memories for other people and probably would not live long enough to have my own, so detachment was inevitable really. There isn't a day that goes by where I don't feel that detachment, even now. For example, I find it really difficult talking on the phone or going out sometimes just in case I die next week. I want to stay a happy memory and for people not to see me when I'm ravaged by one of the many illnesses I've contracted. I guess when my time comes, I'll become more agoraphobic. This situation is wrong; so very wrong.
98. So Basingstoke September 1986 "Do you know how lucky you are to be alive and have free treatment for your Haemophilia?" and would that consultant ask me the very same question again today?. I wish she would because this time I'd have more answers because back then I was voiceless. Yes I really know how lucky I am to be alive but in regards to the 'free treatment', you get what you pay for. Shame on you NHS, shame on you.

99. As a result of my HIV treatment I currently have peripheral neuropathy which means I have debilitating pain in my nerve endings. I also suffer from irritable bowel syndrome. I previously had pain in my right side which was misdiagnosed for years as a stress related disorder and this pain remains to this day.
100. I have never been treated for Hepatitis B however cleared it about three years ago around 2015. The doctors were quite surprised about this and think it could have been cleared as a result of taking the HIV drug Tlevada.
101. I refused all Interferon treatments for Hepatitis C as I am genotype 1a which has a 90% failure rate. The Interferon treatment was offered to me on several occasions and especially when I was around 40 years old. I was treated for Hepatitis C with ABBVIE Sofosbuvir and Ribavirin in around 2015 and I "cleared" the virus following that treatment.
102. I have received five treatments for HIV. Dr Aronstam never gave me AZT as he had strict criteria of a boy's weight and height which I did not meet as my T-cells thankfully held out. In around 1998, a year after my brother Jason died of Aids aged 28, I was offered the double combination of Zidovudine and Zalcitabine for HIV at the Treloar centre as my cell counts and blood tests had slowly declined. My surrogate guardian Maureen Leary received the NAM Treatment Update for AIDS research and treatments which detailed what treatments were and were not working well. She told me about the new treatment involving protease inhibitors so, I moved my haemophilia care to St Thomas Hospital in London, who were able to obtain funding for this as the Treloar centre couldn't. I was then put onto the triple combination of Zidovudine, Zalcitabine and Zalcitabine added to the above to which there were many problematic side effects, but I got through them. I then went onto Truvada, much later followed by 3 months treatment with Truimec in 2018 which had harsh side effects including lactic acidosis. I am currently on Isentress (Tenofovir), to hopefully calm my debilitating peripheral neuropathy due to the long-term use of being prescribed Ritonavir for many years. We are waiting to see if things improve in hope that such damage isn't permanent. I remain on Ictastan (Truvada) for now but I'm soon to be changed from Truvada to Destonivir in hope

to avoid the potential risk of the known bone density issue's and kidney damage associated with Truvada due to its long-term use. My current protocol involves taking three pills a day at this current time.

103. My experience of the care system and permanent placement with the Goodyear's was quite horrendous. I was systematically abused both emotionally and finally physically by certain members of my adoptive family from the age of 8 years old to 16 years. It was my mother (Margret) and **GRO-D** and equally **GRO-D** who mentally and later on physically abused me. Mum and Dad always had arguments after my first Hepatitis B diagnosis as my Mum was a nurse who trusted the doctors and she was adamant that the NHS would never harm me on purpose. She wanted my Dad to calm down about everything, but my Dad would not have it. He refused to accept it and never did.

104. When I moved **GRO-D** School aged 5 the Headmaster told all the children on the first day of assembly that I had haemophilia. From that time on I was bullied. This culminated in attack by **GRO-D** who was a boy at the school, around the Easter term when I was 9 years old. I remember that **GRO-D** checked that I was left handed and then broke my left arm with a metal bar. My Dad immediately took me out of school, and I spent the following year in and out of hospital on morphine while the doctors tried to mend my arm. If I moved my arm when it was in a splint it would start bleeding again. I do not have many memories of this time.

105. When my arm had recovered enough, I remember going to an open day at Treloar's, still with my arm in a splint, around March 1980 with my parents and I was offered a place. My adoptive father had a heart attack on 4 April 1980 and died when I was 10 years old. My adoptive mother told me that I had killed him because of the stress he felt following my Hepatitis B infection and that my father had been the only one who actually wanted me. My Mum continually blamed me for his death, it was her 'goto punishment' as my Dad constantly worried about me and she thought that all the stress and conflict over me killed my father. I was always blamed for his death even at his funeral and many times afterwards. This

is something that has had a huge impact on and throughout my life and that I felt significantly again when I was infected with HIV and Hepatitis C. I will carry that with me for the remainder of my life.

106. From talking to other boys at Treloar's I had a suspicion that I had been infected with HIV long before being told. My mum also suspected this, and she told all the key neighbours of her suspicion. I do not know why she did this as it made life intolerable for me in going home to Portsmouth in the holidays and so on. When I was told by Dr Aronstam that I had been infected with HIV when I was 15 years old, I told my mum of course, but she would not believe me, as she still held onto her virement faith in doctors. However, when she was finally formally told by Treloar's when I was 16 that I had indeed been infected with HIV, our relationship completely broke down. This culminated in further physical violence and the most extreme to date at that time. When I was 16 years old, she physically attacked me over several hours one evening to which, I was forced to briefly defend myself. The local police and social services were involved throughout this period during which, I would contemplate suicide on some occasions. This was mainly due to having no real support beyond what Treloars could offer as, nothing, nothing was done to attempt to change my dire circumstances poorly maintained by the relevant people, professionally trained too, or otherwise. They should have taken better care of me overall in my young but clearly vulnerable early life. Subsequently I was removed from the family home and her 'care' in 1986 and ended up residing in to a children's home for challenging adolescents in Cosham near Portsmouth. It was a relief to be away from the Goodyears at that time and I was going to die young anyway from AIDS so I thought so I went onto live the best I could with the time I had.

107. I was still at Treloar's at this time and spent about 10 months during my holidays in the children's home. However, there was a freedom in being at Treloars, I couldn't wait to get back there as being there, in a roundabout way, ironically saved my life in long run. It was safer than all the alternatives at the time.

108. My Mum could never admit what happened to me.

109. I went through a terrible period after my Mum died in 1987.
110. I was kept back a year due to mathematical dyslexia revealed at age 17, and in my last year at Treloar's, I had resided in a sheltered housing flat sourced and supported by the school via Maureen Leary and Pat Salt amongst others. I then could use the school as a college in my final year of college attendance in 1989.
111. My passion has always been music and I was in school bands. When I was around 17 our school band 'The Traill' won a Department of Health backed national song competition, the final of which was held in the West End. I believe that GRO-D was recruited as a judge, but she pulled out when she realised that two our band members were haemophiliacs. I gigged with bands while I was at Treloar's and after getting 7 CSE's took a course in Music Production and Recording Technology.
112. From around 1989 I fell into a job/role of being a production assistant for many bands and touring shows throughout the UK eventually working for a company called Razzmatazz and NHM Management and Productions along with various others. I worked with many groups and performers such as Status Quo and The Human League for example and was eventually promoted to production and tour manager for one band, Bucks Fizz. It was hard work, but I did well considering an initial hesitancy into taking on such a role. However, maintaining this life whilst keeping my haemophilia and HIV status a secret in a both private and professional sense left me in a perpetual state of fear in being caught out and losing everything I had worked hard towards. It was continually stressful not wanting to be 'discovered' and potentially lose traction in my chosen field but against the odds, life was just like that up to this point anyway on every level. It's all I'd known. I didn't know any different.
113. After my skills were noted, I was offered a golden opportunity by the UK touring firm Entec/SFX to assist with the lighting design and operate for Peter Gabriel's 'Secret World' World Tour in 1993. At the time they were doing some

top line gigs across the world which would have paid approximately £400-£600 a day in today's money. I freelanced and worked as everything from a lighting/set/stage designer up until that point and even though I had worked on a far-reaching array of gigs, a world tour would have been an amazing, even life changing opportunity. But I was given no choice but to turn this down. After some enquiries to the haemophilia society, Dr Wassef confirmed that I would not be allowed into some of the countries due to my HIV status and the insurance issue's surrounding that. I felt my whole career had gone out of the window and It was hard for me to get over the fact that my then and future prospects had been stolen. I have some envy for the jobs my lighting and production friends still undertake to this day but, that said I'm genuinely always happy for them because on the other hand I could be dead but equally, what could have been always stays with me.

114. When I was working for NHM management, I invested part of my 1991 HIV litigation settlement via a financial adviser associated with the company and word got out that I had HIV. Very few people in the company knew but after finding out, my then boss was initially supportive and quite sympathetic which was quite a relief. After the initial shock of my news, he went onto explain that he would always be there for me and my status really didn't matter to him, even going as far as to explain that if was ever unwell I wasn't to worry, and he would get someone to cover the shows. However, like most things that start out with the best will in world wrapped potentially good intentions, a few years down the line when I went off with flu in June 1996, he just never called me again for any further work after maintaining there would be. This was an instantaneous end for my career. I wasn't reprimanded, fired or even let go of, things just fizzled out in a click with no explanation as to why. This was a big deal to me at the time. I felt pretty much both professionally and personally worthless, isolated and an immeasurable failure competitively set against everything I set out to achieve and did so against all the odds. This is especially poignant after it being explained to me by the Treloars career advisor **GRO-D** and also by my Mum that I would never get anywhere in my chosen field of youthful employment but regardless, I still set out to see where I could land, how far I could go and eventually who knows what could have been if I lived long enough during those

most turbulent times but this I will never know. Honestly, it was nice while it lasted though and I mostly enjoyed every gig or show we ever produced.

115. I sporadically do an occasional generic local disco for a charge of £140; however, I have to give £50 from this to my roadie to carry all the sound equipment. It's really not where I wanted to be and hardly aspirational.

116. My HIV and Hepatitis diagnoses means that my life has been lived almost in reverse. It significantly affected my emotional wellbeing during my teenage years and irrevocably altered my expectations, prospects and working life and dreams. I was always worried about letting people down by simply dying on them and struggled to see the point in committing to work but when I did, I 100% committed to any task in hand presented to me, bleeds or no bleeds regardless.

117. On top of that, my ability to think and concentrate has now been detrimentally affected by my infections.

118. I still think, on almost a daily basis, "I'm still here, I'm still alive" and question why often. I suffer from survivor guilt because I have outlived the prognosis I was given. I have also outlived my buddies and peers from Treloar's whom were co-infected and my biological half brothers who were – Jason who died from HIV/AIDS in 1997 and Gary who died from a Hepatitis C related brain haemorrhage in December 2015. We were reunited in 1991 to which I am thankful for.

119. The Hepatitis C caused brain fog. Since clearing the virus in 2015 I have found that I remember more of my past experiences and have more vivid memories of the traumas I have suffered. This has been very difficult for me and I continue to struggle with anxiety and depression. I have also been diagnosed with PTSD.

120. The period 1998 to 2001 was a very difficult three years; particularly the year 2000. I was suffering with PTSD and it took me 9 months to come through what was a very dark time. I still have flash backs now but, at that time, I didn't

want to speak to anyone or answer the phone. I just wanted to crawl away and die.

121. Prior to clearing the virus, I would look in the mirror every morning and check whether the whites of my eyes had turned yellow.

122. Even though I have 'cleared' Hepatitis C post Abbvie, I continue to worry about the effects of my hepatitis infections on my liver and every time I have any abdominal pain I worry that it is liver related. Such pain is another constant. This fear was increased when I had to sign the waiver in the 1991 litigation (discussed later) because it made me realise that my liver was going to be significantly affected.

123. I was very secretive regarding my co-infection status because of the stigma involved and, I am still constantly afraid of what people will say and how they will treat me. I have resided myself to the fact that I may always be but, I have also been more open since being involved with the campaign and media, and since the announcement of the Inquiry but, this has been to the detriment of some longstanding and close friendships due to too many judgments, false narratives unfortunately as many are critical about what others do. One can be only criticised so far before you've no choice but to walk away in cutting the supply to such negativity that often surrounds life.

124. As a result of my experience with contaminated blood I find it very difficult to trust healthcare professionals. I believe that this has been detrimental to my treatment over the years. Whilst I am able to rationalise the fact that most of the professionals, I deal with now were not even working in haemophilia at the relevant time and I do have a good relationship with my current haemophilia team, the fear and doubt never goes away.

125. My partner and I live in poorly maintained rented accommodation but it's by no means the worst. I cannot get a mortgage due to my infections and I'm also in receipt of ESA and housing benefits. If anything happens to me, my partner would not be allowed to stay on in our home due to the structure of the tenancy agreement so would be made technically homeless as well. I never

thought this would be my life, especially being trapped by and having to reside in the social housing system through no fault of my own. This is also particular issue due to the way benefit recipients are generally perceived in the U.K. I hardly tell anyone I'm a benefit recipient due to the embarrassment this entails, and this scenario just adds to the daily stress.

Section 6. Treatment/care/support

126. The AZT protocol at Treloar's was that patients would be given it as a last resort when patients T-cells plateaued below 250 or less. In the earliest days of its inception and availability it was sometimes prescribed on a named patient basis only. Dr Aronstam maintained a hard line on its use so no patient under 16 was prescribed it and even then, the patient had to be of a certain height and weight ratio to meet the criteria. When AZT was prescribed it was given in cautiously and in lower doses than other physicians deemed safe.
127. The only time Dr Aronstam altered his approach was if someone had no other hope or choice. He was frowned upon by other medical professionals of the day. He was no fan of AZT – he knew it was known to have caused toxicity which he described as “very risky to a patient's longevity”. He was often away from the Centre attending conferences on the medications available and potential breakthroughs in treatment.
128. I was never given AZT as my T-cell counts stayed above 600 for longer than most, but if it had been offered, I would have refused it as I witnessed firsthand what it did to people and how it also killed so many people. In 1998. I didn't have any HIV treatment prior to this as I was stable until then. First dual therapy arrived, then triple drug therapy, Haart (which forced me to go to St Thomas's Hospital in London) due to a funding issue at the Treloar center.
129. I was not believed when I told doctors that I had pain in my right side for years and was referred to see three separate psychiatrists. This was due to being repeatedly told that my liver could not actually ache acutely and generate actual physical pain. Given this it was decided the issues were all in my head so I was prescribed Prozac for far too many years. When Dr Corrin Brooks arrived

at Basingstoke Haemophilia centre she said that Professor Thomas has confirmed that some patients with Hepatitis C could indeed suffer acute pain in their RUQ and liver areas. I remember feeling a little vindicated for want of a better expression but, I lost the most trust, if not all trust in the NHS during that period. Mainly due such an abundance of arrogance that I was subjected too, not just for myself, but in other patients who were/are friends too who shared virtually if not the exact same issues regarding Hepatitis C. It became abundantly clear then that what doctors and consultants didn't know and if not found in theirs or a colleagues Medline's, it must be down to my/our own psychology. But, we were and remain first line of co-infected patients so in general, we should be the leading lines toward such learning as to what medical professionals and the science seeks surely rather than having our symptoms simply dismissed right off the bat. This has very much improved over the 15 years or so though and, I've been blessed to know some truly superb doctors in equal measure without whom, I wouldn't still be here today and for that I'm always thankful.

130. Due to HIV becoming more active by 1998, I had a problem accessing and obtaining a new but successful HIV treatment Sequiniver. This was a protease inhibitor medication but due to its cost it was difficult to remain under the care of the Treloar center at the time due to financial constraints on their budget. My platelet count had fallen to just 9 which was also extremely dangerous for a severe hemophiliac so instead, I was prescribed high dose steroids (prednisone 75mg daily) for extensive periods in an attempt to raise and improve my Thromboneutrapenia, which in the interim worked but they had a detrimental and counterproductive effect on my immune system given that fact that such long-term steroids prescriptions, suppressed my immune system even further. It was also rather bad for my joints overall due to the weight gain associated with such treatments and I put on three stones. It was also during this time where I lost many of my teeth due to such high dose steroids and they crumbled. My remaining teeth were removed via a complete clearance under a general anesthetic by a rather despondent but over-jealous dental consultant with a bad attitude. So frustratingly, I also lost my smile whilst still young because of HIV too. However, regarding Saquinavir, it was known to be successful in improving the platelet counts in people with HIV and as the Treloar Centre could not obtain

the funding required for the drug, Dr M. Wassef recommended that I move to St Thomas. There I received excellent treatment from Dr G. Savage. I was provided with high purity Factor VIII, a battery of extensive tests specifically aimed to rule out cancers such as leukemia and the then required Sequiniver was prescribed thus achieving the desired outcome. Despite the laborious gastric side effects Saquinavir managed to restore my platelet count in a relatively short space of time. My condition improved considerably along with a significant uplift in T-cell replication thus rendering me 'out of the woods' in place of any borderline AIDS diagnosis that were destined to become my future given the trajectory of my blood work in that period. I would have remained at St Thomas's but given the immense expense of such extensive medical care being charged back to the Basingstoke health trust, I was eventually given an ultimatum. Either move to the London area to justify the cost made to relieve the financial burden on the Northants Trust, or return to the care of the Northants Trust. Relocating to London wasn't an option at that stage and I returned to Basingstoke after about 10 months. I was permitted to remain on Saquinavir so in a roundabout way the benefit obviously outweighed the stress at the time.

131. I also had difficulties obtaining the Hepatitis C treatment Sofosbuvir around 2015. I had always refused the Pegylated Interferon and Ribavirin approach due to its 90% failure rate for my genotype and hearing from and being witness too some friends how it significantly affected people's mood, let alone its vast array of other unpleasant and advanced side effects. When Sabofivir first became available, I was refused treatment due to its cost and galvanised local my MP Damien Hinds. Shortly after, more money became available for Basingstoke and I was one of four haemophiliacs at who were finally allowed access to the treatment. This treatment cost £36,000 for a 3-month course and again thankfully, it 'cleared' my Hepatitis C. I have been told that I have fibrosis of the liver, but the consultant believes that I have missed cirrhosis; however they cannot be absolutely certain without a biopsy which is naturally problematic and potentially life threatening for a severe haemophiliac.

132. Originally all psychological support was by the nurses and it was terrible. It was always in the Haemophilia Centre and it was rubbish, as the walls were thin,

and everyone could hear. It was awful, very sparse and some nurses I saw were very judgmental regarding the process.

133. We became each other's counsellors and the nurses were drained out for trying to support everyone. I think the nurses should have had their own counselling too. I think counselling would have greatly benefitted me and I probably wouldn't have done some silly things, such as heaving drinking during the period 1991 to 1993. I do not think I would have been like that if I had had counselling. However, any counselling could never have been adequate for what happened.

134. I paid myself for hypnotherapy myself locally with Alison Woodward and it helped me hugely. Around 2010 I self funded about 12 sessions of counselling with Andrew Clark as I felt that I was cracking after the Archer report which was extremely helpful. It gave me straggles to use which I still use to this day. For the last two years I have received counselling from NHS via haemophilia Centre every 6 weeks which has been life changing and affirming.

Section 7. Financial Assistance

135. I was involved in the 1991 litigation and signed the waiver. Initially I refused to sign anything until the final "good cop, bad cop" routine took place. I signed, like others, because I was told otherwise everyone would get nothing. I didn't really know what a waiver was: I was only 19. We were young and naïve and £23,500 seemed like a lot of money to terminally ill young men like me. Three months later the news about Hepatitis C broke.

136. As soon as the McFarlane Trust was set up, Dr Aronstam made sure they came down to visit us and he set up an interview with each of us. Dr Aronstam was obsessed with finances to get us the best support he could. He retained this stance right up until his retirement.

137. The MacFarlane Trust used to give me £79 a month, a mobility grant, a holiday grant £350 a year and decoration grant £1200 every 5 years. Then the monthly amount improved by increments and jumped to about £469 a month

(from £79). The £469 a month saved me financially. I would have been in very serious trouble without it.

138. Then in 2011 I moved into my Housing Association House and with the help of an Occupational Therapist applied for £2,500 to knock through my living room to make it one full through lounge when I moved in. Shortly after I moved in my oven, hoover and washing machine all broke and I applied for grants for these which were allowed at a capped rate. The MacFarlane Trust were quite generous as I had not applied for anything for 10 years, however, the reason for this was because the form filling required for the MacFarlane Trust and Caxton Fund support was arduous. When you feel time is short you don't want to waste it filling in endless forms to beg for support. The MacFarlane Trust turned down every application I made between 2011 and 2015. In 2012 I applied for a Tempa mattress, but they turned me down even with supporting letters from my haemophilia consultant and physiotherapist. I haven't applied for any support provision based grants since that time for the reasons stated above.

139. I do not believe that the charitable trusts were fit for purpose. I've also been subjected to two medically grilling ESA reviews, four DWP compliance checks, requested to be seen by my local job centre regarding my benefit claim and battled against a bedroom tax levy over the last two years alone. I find this very draining.

140. I got stage 1 Skipton lump sum of £20,000 in 2004. My stage 2 lump sum payment was deferred even though my Fibro scan was on the cusp.

141. I also received £20,000 for the US Litigation Pharma in 2009 but consider this to be 'blood money' and have put it in trust for my Godson.

Section 8. Other Issues

142. When I sero-converted in 1983 and was subsequently diagnosed with the social pariah that is HIV as a young teen, life as I knew it ended. The "wonder drug" Factor VIII molded and shaped my future but not in the way it was intended to. For me, my half-brothers and so many friends, it was our death call and

remains so. Entire generations of young men tragically dissipate into that history but remain alive in the memories of the survivors.

143. Financial independence is key to any recommendation made by the Chair of the Inquiry. We should not have to live with the uncertainty of whether payments will be continued by successive governments or following budget reviews.

144. It is time for the truth. There are too many empty chairs in too many family homes up and down the country set against years of confused and blurred lines handed down by successive governments. It is a systemic tragedy.

145. Several cases of potential criminal wrongdoing were presented to the House of Commons by Andy Burnham in his speech on 26 April 2017. These need to be considered by the Inquiry along with the industrial scale cover up.

146. My brother Jason died from complications relating to Aids on September 28, 1997, aged just 28. He was very much a free spirit in the world, strong willed, a little bashful but at the same time confident and above all, a very funny and stylish chap. We were close. Jason was made of steel' and he never believed for a minute he was going to die, right up to the moment I had to tell him he was going to, he couldn't quite believe it. Frustratingly, on his inception at Millburgh Hall in Petworth, the hospice where he died, he was accompanied by only twenty-eight pages of notes provided by the Kent and Canterbury Haemophilia Centre. This equated to one page for each year of his life. The hospice staff had never come across a case like it, it genuinely angered them. They had to source knowledge of his haemophilia treatment plan from me and arranged some hasty reading of some medical books for the other staff. Thank god for the expert haemophilia training that the Lord Mayor Treloar College, provided me is all I can say. Interestingly Jason very nearly attended Treloars in 1978 and again 1979 but there was a funding issue on both occasions, so this wasn't to be.

147. My last remaining brother Gary, passed away suddenly before Christmas on December 4, 2016 due to a brain haemorrhage caused by his

post treatment for hepatitis C. His health just couldn't take any more duress or knocks especially both with him being multiply infected via Contaminated Factor 8. That said before he passed, he was doing better than in previous months leading up to his death, which makes his death so near Christmas so unnecessary and tragic. Before he passed he was fairly well, but he was still angry though at the way we had become infected due to the importation of American Factor 8 at the height of the HIV/Aids crisis and, on the steps of the Grand Hotel in Brighton he said, 'the bloody Americans did this to me, that stuff was filthy'. Three days later he was dead! Gary was a private kind of soul but had a big generous heart, was a killer championship pool player and he loved his bling, his friends, his pet dogs Lucy and Honey amongst many other attributes that made him such a unique person. Life is a mirror, this is my mirror. Faces and voices may dissipate into the dark; we who remain are their light. I'm the last Brother remaining today and likewise, in similar ways to our blood brothers from Treloar school that also perished, the clocks never stop ticking.

148. At the Treloar school in the mid 1970's, the then centre director, a now late Dr Rainsford explained to a later to become one of our haemophilia nurse, Yvonne Stebbings – with a bottle of factor 8 concentrate in his hand that, 'This material is going to revolutionise their lives in so many ways but, it's also going to kill them!' On asking why he explained 'because it's full of hepatitis but what can we do. Factors are coming in we're unable to really stop that happening'. As you can imagine Yvonne didn't know how to respond but, it was a given from the offset that we were all going to be infected, 100% of us, with Hepatis B.

Anonymity, disclosure and redaction

149. I do not wish to apply for anonymity.

150. I am happy to provide oral evidence.

Statement of Truth

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

Signed GRO-C.....

Dated *20/2/2019*.....