Witness Name: Nicholas Sainsbury
Statement No: WITN1800001
Exhibits: WITN1800002
Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF NICHOLAS SAINSBURY

I, Nicholas Sainsbury will say as follows:-

Section 1. Introduction

1. My name is Nicholas Sainsbury and I was born on GRO-C 1963. I live alone at GRO-C. I am single and my parents have passed away.

2. This witness statement has been prepared without the benefit of access to my full medical records.

Section 2. How infected

3. I was diagnosed with severe Haemophilia A following a serious brain bleed when I was two months old, which left me with coordination problems.

4. As treatment for my Haemophilia, I received plasma and cryoprecipitate before eventually moving on to treatment with Factor VIII. I cannot recall when I began treatment with Factor VIII, but I know that I received Hemofil, Lister, Factorate and Kryobuilin products.

5. I initially received treatment on the children's ward of the Hull Royal Infirmary, where I was under the care of Dr Philpott. I was also treated at later dates at the Churchill Hospital, Oxford and the Nuffield Orthopaedic Centre, Oxford, where I was under the care Dr Rosemary Briggs, Dr C Rizza and Dr Matthews.

6. In 1974, I enrolled at the Lord Mayor Treloar College where my treatment was administered by Dr Kirk, Dr McHardy, Mr Aromstan, Mr Wasseff and various nurses. I remained at the school until 1980.

7. Following this, I moved to GRO-C and was under the care of Dr Montgomery and Dr Raper at the Kingston General Hospital.

8. As a result of my treatment with contaminated Factor VIII blood products, I contracted HIV, Hepatitis B and the Hepatitis C Virus (HCV).

9. My first knowledge of problems with Factor VIII, was during my second year at Lord Mayor Treloar College in or around 1975/6, when I was only 12/13 years old. My best friend, who slept in the bed next to mine, woke up and we were laughing that he had turned bright yellow; we had no idea what the problem was. A group of ten boys were then diagnosed with Hepatitis B and by coincidence this happened to be on the day of the school medical. They were told it would take them six months to recover. The rest of us were told that there were two forms of Hepatitis – the fatal kind and the non-fatal kind. The staff informed us that we would be pleased to hear that the infected boys had the non-fatal kind and would recover in around six months. However, it was disconcerting to see that all of the infected boys were forced to bear the stigma of having a small red mark on their meal plates and were required to hand their plates to the canteen staff in person, in order for them to be sterilised.

10. I do not recall being provided any further information and I do not consider that I was aware of the risks associated with blood products.

11. With regards to my infection with HIV, there are two positive results listed in my notes from the Kingston General Hospital, Hull. The first is an HTLV-3 test

dated 2nd July 1986, I am aware that this is an historic name for HIV. The second is a positive HIV test dated 17th August 1989. The notes are unclear as to when I was first informed of my HIV status, but to the best of my recollection it would be more likely to be aftrer the latter test in 1989.

12. My consultant gave me very little information about HIV when he informed me of my infection. In my opinion, he tried to downplay it. However, he stressed the importance of a good diet and consuming vitamins. He told me that he was hopeful that I, and other Haemophiliacs, had only received a small dose of HIV because the blood used was taken from many thousands of donors. He then added "unlike the other lot who get the full blast."

13. I never felt I was given much in the way of information about AIDS and HIV, and I consider that the little information I received could have been given to me earlier. My main source of information was in the form of unhelpful, alarmist media information. An example of this was one of the more downmarket newspapers, which referred to Haemophiliacs as "ticking time bombs."

14. With regards to my HCV infection, the date of my first positive test is recorded as 13th July 1990 and there is no mention of me being informed at this time. I do recall a brief comment by my consultant at the time, who said "you know about this liver thing you have got." This must have been some time in the mid-90s. At the time I was unaware what he was referring to and did not understand that I had contracted HCV.

15. My HCV status is first commented on in my notes on 21st September 1993. It is interesting to note that this was two years after what is referred to as the 1991 Settlement. As a condition of this settlement all of the Haemophiliacs were offered a limited payment on their HIV infection on the condition that they signed away their rights to take any form of legal action in the future for any hepatitis virus that they might also be infected with.

16. There is no documentary evidence or comment in my notes as to when I was informed of any of my infections.

17. My first knowledge of my infection with Hepatitis B, was when I joined a group class action against an American Factor VIII manufacturer in 2003 and I noticed that it had been entered on my claim form. Upon inspecting my medical records, I found a Hepatitis B positive result from 1977, this was found amongst my records from the Lord Mayor Treloar College. I have no recollection of Hepatitis B ever being discussed with me at anytime by my doctors.

18. In order to clarify this, I am exhibiting a copy of a letter dated 14th June 2018 (see WITN1800002) from my Haemophilia Consultant to myself, which sets out all of my dated test results.

19. Given the dates of positive test results as recorded in my medical notes, I believe that there were unacceptable delays in informing me of the viruses. With particular regard to the HCV test result, I was not made aware that I was infected with HCV until years after I signed away my rights to take legal action in respect of it.

20. I believe that there was reluctance by the government to tell us much, as they were concerned about possible criminal prosecution of individuals as this was happening in France. I consider that any information that was given to me was haphazard and totally insufficient. I do not have any recollection of being given any information about the risks of others being infected as a result of my infections.

Section 3. Other Infections

21. I am not aware of having received any other infection or infections, other than HIV, HCV and HBV, as a result of being given infected blood products.

Section 4. Consent

22. Between 1974 and 1980, I was a pupil at the Lord Mayor Treloar College, and we had blood tests taken at the beginning of each term. However, I believe they were for routine purposes, such as testing us for inhibitors.

23. However, I do recall being asked to trial a particular brand of Factor VIII concentrate called Cryoglobin, over the school summer holidays one year. Both I and my local Haemophilia centre in Hull were asked about this.

Section 5. Impact of the Infection

24. The news of my HIV infection was a massive shock, it transformed my life and the lives of all Haemophiliacs. I recall the day that I received this news. It was bright and sunny and I was still enjoying the satisfaction and pride of having recently moved to a new Civil Service Department after receiving a promotion to the next grade on my career path.

25. After my appointment, I went straight back to work and just got through the rest of the day in a haze. It is difficult, if not impossible, to describe my feelings at that shattering time. However, I soon came to the decision that it should be 'business as usual', for as long as possible. Only my immediate family was told of my status and we made the decision not to tell anyone, including friends. Apart from writing to my local MP, we declined to join in with any public campaigning or speak to any media.

26. The knowledge that I was infected with arguably the most feared infectious disease since the Bubonic plague of the Middle Ages was hard enough to deal with. The constant reminders on television and in the newspapers made life very grim. The television adverts featuring a toppling tombstone and the words "don't die of ignorance" were an almost daily feature, as were similar leaflets that were posted to every address in the country.

27. Obviously whilst at work, the subject of AIDS was never far from the conversation. Although I had not informed anyone of my infection, I had to endure childish and cruel jokes about how AIDS was acquired, and listen to them discuss what they would do if they discovered someone had AIDS. These comments came from people who were my colleagues and they were regarded as intelligent people. The girl who sat next to me for two years said "you do not go near someone with AIDS, you make them stand in the corner"

and a man I worked with for a year said that if he found out anyone at work had AIDS, he would "stand in a corner himself and fend them off with a gun."

28. It felt impossible to just ignore AIDS or put it to one side. I felt as though I was waiting for an evil beast to strike at me, at a method and time of its own choosing.

29. Most of the information I received was through the media. I did not know what symptoms to expect. Shortly after my diagnosis, I was prescribed a very large antibiotic tablet called Septrin. This was to protect my lungs against pneumocystitis. This medication was horrible, it was extremely large, hard to swallow and tasted like chalk.

30. Physically, everything was fine for the first few years and hope rose within me that this would continue indefinitely. My first symptoms were night sweats, and nearly every night I would wake up and feel my night clothes and bed sheets completely wet through. I knew from various literatures that this was the first sign of trouble and that my immune system was now under attack. My life as an HIV victim had begun.

31. The first infection of significance came in the form of my mouth, tongue and throat being covered in a white coating. I delayed reporting this out of fear. When I decided to report it, I felt it as if I was foaming at the mouth. It turned out to be oral thrust and was quickly treated with mouth drops. I was told at this time that my CD4 count had fallen below 200 and so I could expect to start getting more infections. I asked the consultant if I should be referred to an AIDS specialist. I worried that he would say "you are going to die." The reply was merely "we only send you to see one if you get an infection we cannot cure."

32. I was given no further advice and went on to have further infections of thrush and eventually facial herpes, which meant painful awful sores all over my face. This struck a terrifying chord within me, as I had seen on a television news report a photograph of a boy I had met during my time at the Lord

Mayor Treloar College; his face had been blighted with terrible sores before his death.

33. In terms of opportunistic infections, I have been comparatively lucky compared to some contaminated blood victims. The infections previously referred to having cleared up through the use of antibiotics, although routine colds have often developed into chest or throat infections which have required two or more courses of antibiotic therapy.

34. By 1996, my overall health was severely compromised. I was on the waiting list to have both knee joints replaced and was living in extreme pain, bent double and going to work on crutches. I went for my pre-operation assessment in Leeds and the Haemotologist informed me that he was not happy. My white cell count was very low and he had not been told about my upcoming surgeries. I was advised that it would be dangerous to proceed with my blood in the condition that it was. Fortunately, I was able to have surgery a few weeks later but had to take a drug known as GCFF to improve my cell count. Although this drug achieved the desired result, it was horrible and caused me to suffer side effects including headaches, diarrhoea, skin rashes and permanent tiredness.

35. Following the first operation, I was left with an infection of cellulitis and my left leg turned pink. I jokingly said to the doctor "I won't lose my leg will I?" his reply was "well I don't know at this stage." After the second operation, I had a similar infection of cellulitis and was in hospital for a total of four weeks. I returned to work several months after the second replacement, but no longer had the energy or strength to continue working.

36. At this time, I was working at the Hull District Land Registry, which was my dream job. I had recently been given a promotion and I was learning to drive. However, I could not concentrate physically or mentally anymore. I was suffering from sweats all the time and felt generally unwell. As a result of this, I took medical retirement in late 1997.

37. By the time of my retirement in 1997, my condition had deteriorated. It got so bad that one week I was completely disorientated and I got up in the middle of the night to go to work. My brother and the rest of my family became alarmed and thought I had had a stroke or massive infection. My brother called the hospital and demanded that I see an AIDS specialist.

38. I was seen by Dr MacLean at the Hull Royal Infirmary, he was alarmed at my condition and told me that I had come just in time. I was so weak at that point that he had to support me as I walked into his office. I told him how I felt, and then he took blood tests and told me that the HIV was making me very ill. He started me on a course of anti-retrovirals, which I found out had been available for sometime before.

39. Within a few weeks of the HIV therapy, I started to feel a lot better. Since I first started treatment in 1997, the treatment has changed and has greatly improved. Although the exact treatment has changed, I have permanently received some form of treatment for the last 22 years.

40. I found that the early regime of treatment caused me to suffer from severe headaches, insomnia, diarrhea, tiredness and depression, to name but a few. In addition to this, treatment with a drug called Hydroxyurea in the 1990s caused my haemoglobin to drop. This led to me feeling breathless and it was painful to move at all. I spent a week in hospital, in order to be stabilized. Around a year later, I read an article about this drug which said it should not be given to HIV/AIDS patients.

41. I was also prescribed medication that has caused me to have thinning of the bones, although this has not formally been diagnosed as osteoporosis. This, in combination with my Haemophilia, poses a risk to my health; I constantly worry about falling or stumbling.

42. Given all of the problems I was having with HIV, my HCV was pushed to the back of my mind for many years. Eventually, however, I was advised that I needed to undertake a course of treatment to attempt to clear HCV from my body. I was invited to attend the hospital to learn how to administer part of the

treatment, which had to be injected under the skin in conjunction with taking several tablets each day. The injection was Alpha Interferon and the tablet was called Ribavirin.

43. I was shown into the consultant's room, only to find another Haemophiliac sat in the room, whom I had met only once previously. Immediately, the confidentiality of two patients was broken. I was shown how to use the treatment, which involved breaking a glass vial in two and drawing up the medication therein. I was disgusted that there was no regard for patient confidentiality and privacy. I enquired about side effects of the drugs, to which the consultant replied "don't be silly, it only lasts for a few days, just a headache."

44. My first attempt at using the Interferon at home led to the glass vial breaking and badly cutting a finger on my left hand. This resulted in me needing three stitches and leaving me with a scar on my finger for life.

45. After a few months of the treatment I was diagnosed with chronic depression, which I was told was a common problem with this drug. To this day, I still need to take anti-depressants.

46. After a 48-week course of the treatment, I was informed that it had been unsuccessful and had not cleared the HCV from my body. Many years later, I was registered as having stage two HCV. So far I have been lucky, in that I have only a small level of cirrhosis of the liver.

47. The story of Treloar's, and the grim deaths of seventy three former students who were killed by contaminated Factor VIII, which was intended to enhance their lives is a tragedy within the tragedy of the Contaminated Blood Scandal in this country. The lives of those who died is commemorated in a beautifully designed stained glass window in the School Chapel and those sixteen of us who have survived continue our campaign for truth and justice. Our story has featured in the Sunday Express and the Mail on Sunday and the BBC devoted most of one episode of their flagship current affairs programme "Panorama" to the story. Our efforts continue on this story along with all the other many

aspects of the disaster. I do wish to make clear that none of us apportion any blame to the medical staff at the school whom were always supportive and made every effort to look after us all. We believe that Treloar's was singled out for non consensual trials of previously untested Factor VIII concentrate and look to the Inquiry to uncover the truth of what happened. We hope that we get not only the answers to these questions but the answers to all of the many, many issues that have been raised by the Contaminated Blood Scandal. We have already waited thirty years and for far too many people, time has run out. "Justice delayed is justice denied".

48. When talking about the effects of the Contaminated Blood Tragedy, it is only natural to focus largely on our families and friends. Sadly, countless others have had their lives blighted and I must pay tribute to one of them. One was a Haemophilia Nurse at the Lord Mayor Treloar College at Alton in Hampshire who helped look after approximately 90 Haemophiliac boys (including myself) in the 1970's and early 1980's.

49. Her compassion and care in her work of infusing and caring for us when we had a bleed and her patience when training us to self infuse factor 8 and care for ourselves more independently in preparation for when we eventually left school won her a special place in all our hearts. I was therefore saddened to hear some years ago that, following her much deserved retirement; she was reluctant to accept visits from her former "boys", because she felt a terrible weight of guilt for injecting us with contaminated factor 8.

50. None of us blamed her or any other member of the medical Team at Treloar's. We all loved her and I was relieved to hear from another former Treloar boy had managed to visit her a few times before her death and had put her mind at ease. She was in many respects a victim herself despite not being infected.

Section 6. Treatment/care/support

51. I have never been offered any counselling or psychological support. I believe I would have found it useful to have someone independent to talk to in the early days when I feared for my life.

52. I was given access to an HIV social worker for a few years, but in my view this does not qualify as psychological support.

53. Eventually I sought my own support. I joined a local Body Positive support group, but I was the only Haemophiliac there and I felt a little out of place.

54. I am now at a point in my life where I have lived with this for so long and lived through so much, that I feel that I have enough support in my brother, my friend Andy and the people I talk to on online forums and social media.

Section 7. Financial Assistance

55. From around the late 1980s, I began receiving £20 a week from the Macfarlane Trust for the additional costs of living with HIV/AIDS.

56. Along with all Haemophiliacs and their intimate partners that had been infected, I received an ex gratia payment of £20,000 which was announced by Margaret Thatcher after the government faced pressure from MPs of all parties.

57. In the 1991 Settlement, I received a further £23,500. However, in order to receive this payment I was forced to sign a waiver to waive all rights to take any further litigation against them for any Hepatitis virus that I may have contracted as a result of receiving contaminated blood products.

58. I received various other payments from the Macfarlane Trusts and also single-item grants. The range of grants included: a washing machine, deep freezer, household items, the deposit towards a mobility car and more recently I received a sum towards moving costs and building work that was required when I moved house.

59. Like many people I found the staff at the Macfarlane Trust to be uncaring and unhelpful. Communication was very poor and their attitude was on of "you should be thankful you are getting this money."

60. When I was informed of my diagnosis of Hepatitis C, I received a lump sum payment of £20,000 from the Skipton Fund. Around six years ago, following an examination of my liver scan results, I decided to apply for Stage 2 status. My application was successful and I received a further £50,000 lump sum payment and ongoing monthly payments for my HCV Stage 2 condition.

61. The schemes have always operated in quite an arbitrary manner and the staff were not always very helpful or approachable. Although the financial support has improved in recent years, I feel that we have been made to fight for every penny for a period of thirty years, whilst at the same time we have watched people die without receiving any support at all.

62. Around 16 years ago, a group action was started in the UK by several hundred Haemophiliac patients against the drug manufacturers responsible for supplying the contaminated Factor VIII. We were told when this began that the process would take two years and we should expect to see a payment of around £200,000. The case dragged on for ten years and we received payments of just over £20,000.

Section 8. Other Issues

63. Shortly after the American Litigation began, I got involved in the main campaign. Over these many years I have been involved with other campaigners in holding demonstrations both in London and Whipney. I have attended meeting with MPs in the Houses of Parliament. We won a narrow point of law in the High Court many years ago; interestingly, the judge turned round and said to the government barrister "why have these people not been sorted out yet?", the barrister replied "why should they be? The government does not see why they should." This caused uproar in the court room, but also gave us some insight into the government attitude towards this.

64. The campaign continued and I joined in many meetings with the Department of Health, the Macfarlane Trust, MPs and government ministers. All of this required extensive travelling. For example, last year I attended around nine meetings all over the country, including the Preliminary Hearings to the Inquiry in September.

65. I have been involved in obtaining documents for the Inquiry, I have participated in various research projects and I have asked questions at meetings on behalf of the community. In particular, I have put many questions to the EIBSS and the Department of Work and Pensions. The answers I have received have given me the impression that these meetings are worthless until a decision is made at government level to review the existing financial support system.

66. My greatest fear is the current Inquiry will be hindered by the absence of so many vital documents. There has been much talk in the media recently of missing files turning up and other vital files supposedly destroyed by junior members of the civil service. I believe that much of this was done deliberately. I feel that much of the cover up is because there were criminal prosecutions taking place in France when it first unfolded and that the government is frightened of the possibility of having to pay full compensation if the entire truth comes out.

67. I can only hope that the Inquiry will be successful in getting to the truth, as it is our last chance. We want full and frank disclosure of errors made by individuals or organisations, no matter whom or what they may be. I believe those that have suffered should receive full compensation, but also a guarantee that their existing payments will continue for life. We should be exempted from any further distressing social benefit reviews, which have caused so much distress to an already damaged community. No stone must be left unturned in our quest for the truth, as justice delayed is justice denied, and it has already been denied far too long. We are literally *dying* for the truth.

68. I would like to dedicate my statement to my late parents, Mollie and Brian, who have travelled so much of this terrible journey with me, with nothing other than unconditional love and support.

69. I would also like to dedicate it to the boys of the Lord Mayor Treloars College, who were infected as young men, and whom by the time they left school had unknowingly lived half their natural live span due to this dreaded catastrophe. Out of 89 Haemophiliac boys who attended the school, I am one of only 16 left. This story is as much theirs at is mine.

70. Pursuant to paragraph 2.9 of the Notice of Determination in the Award made to my Solicitors preparation of this statement does not give cover investigative work. I would like to give evidence on the matters set out at paragraphs 64 & 65 above but I am unable to do so in this statement.

Anonymity, disclosure and redaction

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

Statement of Truth

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

Signed... GRO-C ....

Dated.....26/2/19......................