Witness Name: Steven David Clarke
Statement No: WITN1156001
Exhibits: 8
Dated: September 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF STEVEN DAVID CLARKE

I, Steven David Clarke, will say as follows:-

Section 1. Introduction

1. My full name is Steven David Clarke. I live at GRO-C GRO-C My date of birth is GRO-C 1958. I have been married to my wife and caregiver, Christine, for 37 years. We have three children aged 31, 29 and 28 and two grandchildren aged 7 and 18 months. I was born in GRO-C and my wife in GRO-C. We grew up in Essex and married in 1982. In 1983, we started our own business and in 1994 we moved to America. Currently I teach piano, voice and music theory two days a week.

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

Section 2. How Infected

3. I have suffered with mild Haemophilia A with a 14% clotting factor deficiency, since birth.

4. On 12 July 1961, at the age of three, I was admitted to St Andrew's Hospital in Billericay; where I underwent a surgeon's knife to correct a hernia in my groin. The doctors did not discover that I was suffering from haemophilia at this point, despite my bleeding lasting slightly longer than usual. I am told on one occasion my bleeding lasted a total of 4 minutes and 4 seconds. As I was learning to walk, it was noted by my mother and my older sister that I sustained a number of unprecedented bruises and cuts, which seemed to take longer than normal to heal.

5. In 1966, when I was approximately eight years old, I was taken to the dentist by my sister, Marilyn, aged 12 at the time. I underwent a tooth extraction performed by Dr Blake at Dr Blake's Dental Practice, close to our home in GRO-C Following the procedure, the bleeding again did not appear to stop. I awoke the next morning with a large blood clot on my tongue, attached to the cavity where the tooth had been extracted. I was taken back to the dentist and remember a lot of raised voices.

6. Soon after, I was referred to the doctors at Oxford Hospital, where I was eventually diagnosed with mild Haemophilia A. I had no idea what it was, but I was given a little green book that told me so and had my blood group written in it, along with my name.

7. Over the next few years, if I was injured, in need of surgery or had bleeds in my muscles or joints, I would receive treatment. I began to receive cryoprecipitate and/or Factor VIII concentrate during my childhood, mainly at the Whitechapel Hospital, where I was under the care of Dr Turnbull and his understudy, Dr Bolton.

8. On 26th March 1974, I was admitted into Whitechapel Hospital, under the care of Mr McKelvie for a rhinoplasty. A year earlier at the age of 13, I was playing outside with some friends in our neighbourhood when I was punched in the face by an enraged 28 year old man. I suffered a severe broken nose and as the blow had disfigured my face, I incurred breathing problems. Thus the rhinoplasty was deemed necessary.

9. The surgery was far from a success and to this day, my nose is still disfigured and the breathing problems still exist. Before and after the surgery, I would have been given Factor VIII concentrate or cryoprecipitate twice daily.

10. I was discharged from hospital on 1st April 1974, but on the same evening I suffered uncontrollable bleeding and was rushed back to the hospital. On 2nd April 1974, I received a further 25 packs of cryoprecipitate and five bottles of Factor VIII concentrate.

11. My nose bled for the rest of the night and did not stop bleeding until 10am the next morning. I then received ten packs of cryoprecipitate everyday until I was discharged on 8th April 1974. A medical summary of this incident has been exhibited as per **WITN1156002**. Moreover, it is fair to say that I was infected by the Factor VIII concentrate I received during this hospitalisation.

12. During the next few years, several injuries occurred; one quite severe to my left thigh, when I fell down a muddy embankment and landed on a jagged concrete slab. At first I thought my left thigh was broken. I was treated with Factor VIII concentrate and attempted to return to work and normal activity too early, worsening my internal bleeding. I returned again for more Factor VIII concentrate and when the doctors insisted I needed bed rest, I was admitted to Whitechapel Hospital. I stayed for approximately 7 to 10 days, with Factor VIII concentrate being administered everyday to allow the wound to heal.

13. A few days after my grandmother's death on New Year's Eve in 1981, I was admitted to Basildon Hospital due to a cyst that had ruptured on the right side of my lower back. I was in the hospital for approximately a week and received either cryoprecipitate or Factor VIII concentrate at both 9am and 9pm each day. One evening, a male houseman came to administer the treatment and I noticed this time it looked different in colour. Usually the product was orange and pure looking, but this time I noticed strands of red or 'blood' inside of it. This seemed odd so I mentioned it. Within the hour, I suffered a severe allergic reaction. My temperature soared, my body began to convulse and I became very stiff. I curled up into a foetal position, all the while shivering from chills. All my blankets were taken off from my body by the nurses and fans

were put on to regulate my temperature. I could barely speak, but told the nurse I was freezing cold and asked why she was putting fans on me. I can't remember her explanation. A doctor was alerted and came to monitor my condition immediately. This went on into the early hours of the morning. It's funny looking back, I felt like I had done something wrong, in reality, it was my body reacting to the fact that I was probably being injected with something similar to poison. I have a blurred memory, but with each Factor VIII concentrate dose, I was given an antihistamine or similar product to counter any reaction.

14. I was again admitted to Basildon Hospital a year or so later, due to an injury to my chin and inner mouth following a fist fight. I was admitted to hospital and received cryoprecipitate and/or Factor VIII concentrate treatment on this occasion too. I only stayed one night and returned to Basildon Hospital's A&E department for more treatment the next day or so.

15. During my school days, I was placed in a special school in Westcliff, near Southend, Essex, due to my numerous absences at a normal secondary school. I got a great education at this private school. From 1974 to 1976, I went on to Thurrock Technical College where amongst other things, I studied Music. From 1976 until 1979, I was a full time musician and was signed to DJM Records (Elton John's label) I toured all of Britain, Scotland and Wales playing keyboards with a pro-touring band.

16. For the next few years I became involved in retail sales of musical instruments, in particular organs, pianos, keyboards. I went on to work for a company in Southend for several years (who later would become our competition.) My morning regime would be to wake up with body aches, flu symptoms, sore throat and sometimes just washing my face in the morning was enough to trigger a nose bleed. I would drive from Basildon to Southend, trying not to get blood on my shirt or tie and be ready to work at 8am.

17. In August 1982, I married Christine. We have been happy together for the past 37 years, with three grown up children and two wonderful grandchildren. In 1983, we opened our first musical instrument store in Billericay. The

following year we opened a store in Westcliff and the year after that in Basildon. We also went on to open a store in Lakeside Shopping Centre. For around 11 years during the 1980s and early 1990s, we were in business across four stores all over Essex.

18. I always had a passion for sports cars and started to travel to central Florida and began purchasing and importing classic American cars to the UK. This was during the late 1980s and early 1990s and my wife and I were flying as often as five/six times a year into Orlando to purchase vehicle inventory.

19. During the early 1990s, my music business was producing less revenue and blame was placed on me being perpetually sick and being away. At this time, I was finding it harder and harder to stay on top of things. I was a busy guy, but this perpetual feeling of malaise, tiredness, chronic flu symptoms, nasal drip, sore throat, chesty cough, body aches and pains just never left me. I attributed it to the pace of my life.

20. Facing diminishing numbers in 1994, we closed our music business and in the same year immigrated to America. During our trips to America, Christine and I noticed some relief in my symptoms, in particular with the respiratory symptoms and the warmer weather just seemed to suit my bones.

21. We immediately set up business licences, rented a home, place of business and got to work. The climate seemed to suit my symptoms better and it was certainly warmer, improving our overall enjoyment of life for a while.

22. For the next nine and a half years, my wife and I worked very hard and raised our children without trauma. I was still trying to shake off the persistent sore throat, cough, nasal drip, body aches and flu symptoms, but had learned not to blow my nose quite so hard and I avoided nose bleeds in this way. In the early 2000s, weakness and illness started to show through. I became less active in my own business and hired a general manager to relieve me of some of my duties.

23. During this time, we had private health insurance, paid for by our business (medical needs are not free in the USA.) Our insurance carrier was Aetna, we

paid $660 per month for our family plan, which covered the five of us. In the early part of 2003, I went to see my GP to get yet another prescription for my flu like symptoms and my doctor suggested getting a full blood test, to which I agreed.

24. The results from the blood tests came back as positive for Hepatitis C. I didn't know what it was and as my head was spinning with questions. We needed answers immediately. We turned to the internet for research which shows it can be contracted by sharing needles or doing drugs (well that didn't fit,) promiscuous sex, (no,) via blood transfusion. Now we were getting somewhere.

25. At the time, my silent fear was if I had infected my wife or my beloved children GRO-C GRO-C I reached out to the Whitechapel Hospital in London to see whether they could shed any light on the situation.

26. At the same time, we received a letter from our healthcare provider, Aetna, confirming they were no longer covering small businesses. For six years we were paying them $660 per month and had never made a claim and yet, as soon as I was diagnosed with Hepatitis C, our policy was cancelled. Is this the healthcare provider way?

27. I was now facing a serious illness, my health was failing and I had a business that required more and more of my attention. My wife and I went into "damage control mode" and tried to work out the impact the news would have on the people around us, our business, social life and our children at school, if the uncontrolled word got out.

28. At this time, I was very much involved in the community and was a Cub Master with the Boy Scouts of America. I had over 100 boys that looked up to me and my two sons were Cubs too. My staff members at work were not told; only certain family members, if deemed necessary, were told.

29. As I took more time off work to deal with my worsening health issues, the negative effects on my already strained business continued. By the latter part

of 2003, we GRO-C were forced to close our classic car business.

30. In October 2003, I received a letter from Whitechapel Hospital, as per exhibit **WITN1156003.** The letter was from Dr Colvin, head of the haematology department, confirming that I had indeed been given contaminated Factor VIII concentrate on 2nd April 1974.

31. I was not given any information in relation to how to manage my infection. I was advised by the doctor to seek my medical records and contact the Haemophilia Society, The Skipton Fund and The Caxton Fund, which I later went on to do. Following this, I was not provided with any more correspondence.

32. I have never received information about the risks of receiving blood products. When I was young my mother would have always been the person to take me to the hospital and she never received any information either. Moreover, she still has the same telephone number and lives in the same house and still has never been contacted.

33. I was never offered words of sympathy or anything resembling an apology from the medical practitioners following my diagnosis of Hepatitis C. In fact, my only contact was with Dr Colvin.

Section 3. Other Infections

34. I am not aware of having received any other infection from the contaminated blood products.

Section 4. Consent

35. I believe I was tested without knowledge and thus implying I was treated without consent.

36. I cannot recall any conversation, whereby risks of the products were ever discussed.

Section 5. Impact

37. As a young man and throughout the years, my health has always been an uphill struggle. From the mid to late 1970s, I suffered greatly from constant cold and flu like symptoms, weakness, fatigue and immune deficiency problems.

38. In my medical notes from the period of 1983 to 1994, (as exhibited under **WITN1156004**) there are repeated notes of the following symptoms; headache, sore throat, cough with phlegm, ulcerated mouth, tender glands, exhaustion, chest pains, sinusitis, tonsillitis, epiglottis tenderness, pharyngitis, laryngitis, epistaxis, fainting, feeling tired, extreme fatigue and severe body aches and pains.

39. Closer inspection of these notes will show commentary such as, SGOT, SGPT still and an arrow pointing upwards, abdominal pains after drinking a shandy, blood pressure was noted at 120/80 and "liver enflamed" This in particular was not mentioned to me.

40. Until recently I had never seen my medical records or these few selected samples of my GP notes. There are at least twice as many, if not more of a similar thing. What they illustrate and confirm to me is a pattern of continual sickness, far more often than I had first realised. At this time, the virus had manifested in my liver for 10/15 years and despite continual sickness, he chose not to share this information with me. Where did his loyalties lie?

41. I would like to point out the fact that my doctor, on a regular basis it seems, was testing my blood for Hepatitis; he was doing so without knowledge or consent. Furthermore, at no time do I ever remember him saying, we are drawing blood specifically to test for Hepatitis.

42. During the late 1980s and early 1990s, the closest facility that could handle Factor VIII concentrate to my home was the Mid Essex Health Authority, Broomfield Hospital. As previously mentioned, when I had a bleeding disorder or was in need of Factor VIII concentrate, I would go to Broomfield Hospital to be cared for by Dr Hazel Baugh, the Consultant Haematologist.

43. On 15th July 1986, Dr Baugh ordered laboratory work and I noticed a stamp in bold type the words "Danger of Infection." Please see exhibit **WITN1156005.**

44. Dr Baugh's report dated 17th July 1986 concerning the blood work results, state AST and ALT numbers as elevated from normal, as per exhibit **WITN1156006.**

45. Dr Baugh's expert report dated 22nd July 1986, is a letter (exhibited under **WITN1156007**) from Broomfield Hospital signed and addressed to my GP Dr J Patel, discussing me. The first time I saw this letter I was literally stunned. Whereby Dr Baugh writes that she has not mentioned the liver function tests to me. I literally broke down and cried the first timed I saw this document. I cannot explain the amount of faith and trust I had in this professional woman.

46. Throughout my childhood, haemophilia was my biggest health concern. Then as a young man and all through adulthood, I felt my health was constantly under attack. I kept myself super busy, studied hard, worked hard and eventually met the girl of my dreams. Not knowing that I was sick, I never stopped for a single day and felt sorry for myself or considered this was anything more than growing pains and as us British do, just jolly well got on with it!

47. My wife and I were totally committed to raising our family and providing the best life we could for them and ourselves. Waking up every morning and concealing how I really felt became the norm and I became quite good at it.

48. I just seemed unable to recover properly from all of my health problems and was unable to do anything at all for my health issues. On some days I felt like I was unable to battle it all and other days extra effort was needed just to function normally. This occurred most days.

49. Before the move to America and before having children in the early 1980s, I felt my health deteriorate significantly. I suffered sinusitis, bronchitis, numerous throat and chest infections and extreme fatigue. Even still, my wife and I were heavily involved in our businesses and remained busy people.

50. I just seemed unable to recover properly from all of my health problems and was unable to do anything at all for my respiratory problems. On some days I felt like I was unable to battle it all.

51. My morning regime consisted of my getting up, having breakfast, dealing with a nosebleed, driving to work, trying to stop the bleeding and attend a meeting with a cotton bud up my nose.

52. Despite my health troubles, both the music business and the export/import of the classic cars business seemed to be going well.

53. In approximately 2003 and as I became more and more ill, we had to close the business. I was hoping my children would pick up the car business but they were only 15, 14 and 12 years old at the time. I did not have the health to do what I had to do, to keep it running any longer. After I received the news from Dr Turnbull; I decided to turn my life around and knew I needed to make my health a priority. As I was unable to work, it resulted in the bankruptcy of my previously successful business.

54. Following the news of my diagnosis, I began to alienate myself from the world and distanced myself from my wife. I felt I had to prove to her that I did not partake in any extramarital relationships or that I had been using drugs. It was wrong. My relationship suffered immensely as a result. We needed answers fast, before our marriage itself could be destroyed by thoughts of infidelity and the like.

55. I was shocked at the thought that I may have infected somebody else too. I had not known about my infection for just under 30 years and as a musician

and throughout my college years, GRO-C
GRO-C

56. After I was told the truth about my infections, I contacted the hospitals in London. I received a letter from B T Colvin, Senior Lecturer in Haematology dated 23rd October 2003 which stated "I have no doubt that your Hepatitis C infection was related to your haemophilia care" and that I had received Factor VIII concentrate on 2nd April 1974 when it is suspected that I contracted the virus. I was only 15 years old at the time.

57. Following this, I was told to get hold of the haemophilia society and to contact The Skipton Fund and The Caxton Fund.

58. Eventually I was offered treatment consisting of Interferon and Ribavirin. It was offered to me for free and although I came very close to agreeing to it, I refused, as I believe I was only offered it for research purposes and to be their guinea pig. Additionally, I'd heard horror stories of the side effects this treatment caused.

59. Following numerous requests, I received only a small proportion of medical records on 7 July 2004 and quite recently was told the rest were no longer available as they had been destroyed, as per exhibit **WITN1156008.**

60. Upon review I note the medical records I do have, have been marked with "Danger of Infection" which suggests to me that a risk of infection had been known a long time prior to when I found out; please see exhibit **WITN1156009.** I find this infuriating! Furthermore this lack of disclosure or delaying tactic has denied me the opportunity to treat the disease in its' early stages.

61. I also refer to a letter dated 22nd July 1986 from the Mid Essex Health Authority, Broomfield Hospital from Dr Baugh which states that I was not informed of my liver function tests. I find this unbelievable and extremely alarming.

62. I recall that Dr Baugh was reluctant to give me cryoprecipitate and Factor VIII concentrate. She did not explain why, but she said she would prefer to give me the DDAVP instead.

63. More recently, my GP in America, Dr Zalinski, advised my viral load was in the millions and referred me to Dr Haq who was a specialist in the area. Dr Haq confirmed that my genotype 4c, came from India and the proposed medication, Harvoni, did not have the best success rate with this genotype. Each pill was to cost around $1000, so for a course for a month, it would amount to $31000.

64. Even still, in October 2018, I was sent the first batch of Harvoni via courier. My other medication had to be baselined and I had to maintain a healthy diet. At this time, they were doubling up on blood tests. The first blood test showed improvement. In November 2018, the virus had started to fight back which made us all very worried. I took the last pill on Christmas Day and after 30 days, my blood was tested and it was confirmed my viral load was at a normal level. I am currently tested and monitored every 90 days.

65. I was holding one of my tablets and I said to my son that it was unbelievable that this little tablet cost $1000, but only $4 in India.

66. The good news is that the virus is no longer in my blood. The bad news is that I have cirrhosis and a rotten liver which was confirmed by a scan. I was hoping to see some improvement following the Harvoni treatment.

67. I am currently on eight different medications to get me through the day and combat symptoms such as muscle cramps, high blood pressure, problems with nervous systems, neurology, heart, etc.

68. I have an elevated level of creatine kinase enzyme which means that I constantly battle cramps. This level of enzyme is due to the infection and damage in my liver. I thought it was to do with my old age but my GP advised that this is not the case.

69. Even now I have a swollen abdomen but do not drink alcohol or smoke cigarettes.

70. I was diagnosed with Stage 4 cirrhosis and was told that my liver is so damaged and beyond repair, because it has been carrying Hepatitis C for 45 years.

71. The diagnosis shook the very foundation of our life. With my diminishing health GRO-C we were thankful to keep our marital home. We still continue to live conservatively and have managed to raise three great children throughout it all.

72. Despite this, the infection affected my whole family and my children went through a roller-coaster ride. My wife has been a great support system. I have been to some dark places because of all that's happened. She offers me the best support both mentally and physically. On days when I am in a lot of pain she's the one who helps me put my trousers on.

73 GRO-C

74. In the past I've had issues with being stigmatised. On one such occasion I was nine years old and my headmaster, Mr Bell, said "Steven Clarke stand up." He continued to say "no-one is to play with this boy, as he has a bleeding disorder and if he gets cut or bruised, he could bleed to death and we don't want that happening at this school! You may sit down Clarke". I was devastated because I was a sporty boy and I wanted to compete in sports tournaments. I had to be the toughest and best soccer player, runner, high jumper, long jumper and relay runner the school had ever seen. I even went on to represent the school in all these sports. It was later discovered I had a good singing voice and so I joined the school's choir for special events around Christmas, Easter, etc. I also excelled in swimming, which was a low impact sport. Frozen peas and ice cubes were a saviour!

75. When it was discovered that I had Hepatitis C in 2003, my insurance provider dropped us. I did not have health insurance for a long time. It was only when Obama became president that he changed things and levelled the playing field which enabled me to get health insurance, costing $1200 per month.

76. The infection was always kept secret and I do not discuss it with anybody apart from my immediate family and the doctors. It even feels very strange talking about it right now.

Section 6. Treatment/Care/Support

77. I have never been offered any counselling or psychological support as a result of being infected.

Section 7. Financial Assistance

78. I have never received financial assistance from the Haemophilia Society.

79. Following the news of my diagnosis in 2003, I contacted The Skipton Fund and was advised I had to attend a physical examination, if I wished to be considered for monetary compensation.

80. I received the Stage 1 payment from the Skipton Fund in or around 2004 and the Stage 2 payment in or around 2008.

81. I also received financial assistance from The Caxton Foundation, whereby I was given quarterly payments. These began in or around 2004. This has recently changed to payments from the EIBSS; whom I now presently rely on for financial assistance.

82. I continue to receive annual Winter Fuel payments.

Section 8. Other Issues

83. How many times does the Inquiry need to hear that the medical practitioners admitted to fault? There is undisputable liability! I can only question whether there was a conspiracy against the disclosure of facts.

84. People cannot get away with any of this. How could we have had no knowledge for 30/32 years?

85. I look back at all the opportunities that the medical practitioners had to inform me of my infection and cannot believe I was never told. My mother lives at the same address as she did when I was a young boy. However at no point, whenever they realised, in the 70s, 80s, 90s, 00s, did they contact me to let me know. It is unacceptable. Why was I not sent any correspondence? Why was there no testing conducted for so many years? What sort of a human being lets someone who is infected carry on living in that way?

86. "I would like the wrong to be righted."

Anonymity, disclosure and redaction

87. I do not wish to apply to retain my anonymity.

88. I wish to give oral evidence to the Inquiry.

Statement of Truth

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

Signe GRO-C

Dated October 7th 2019