Witness Name: Simon David Chandler
Statement No.: WITN0816001
Exhibits: **WITN0816002**
Dated: 27 July 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF SIMON DAVID CHANDLER BSc MSc

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 25 February 2019.

I, Simon David Chandler, will say as follows: -

Section 1. Introduction

1. My name is Simon David Chandler. My date of birth is GRO-C 1965 and my address is known to the Inquiry. My intention is to put on record how I was infected with HIV, Hepatitis C and Hepatitis B through contaminated Factor VIII. I will focus in particular on my HIV infection and the impact this has had on me and family.

2. I have an aptitude for the physical sciences, principally chemistry (BSc) and later I completed a Masters in Engineering. I am currently

unemployed as I am unable to work due to my illness and therefore failed to develop my career any further, i.e. forgetting about transesterification, which is relevant in the production of biofuels. I live in my own house in Coventry. I am not married and I do not have any children; however, my parents, Joy Chandler (WITN0825) and David Chandler (WITN0824) are the core of my support, otherwise I would have left Coventry in pursuit of a career path, initially in agrochemicals. My parents are also providing statements to the Inquiry.

3. My HIV infection has had a significant impact on my health and potential career, as it puts existing relationships under strain and makes future prospects less likely. It has had a negative impact concerning my relationship with my Lord and Saviour and yet my redeemer lives, which is lost on my parents.

Section 2. How Infected

4. I was diagnosed with Haemophilia (A) at thirteen months old. I have a Factor VIII level of 2.4%, which is classed as borderline moderate to severe. There is a history of haemophilia in my family up to my great, great grandmother, who was a carrier. My mum, Joy Chandler, is also a carrier GRO-C GRO-C

5. Having haemophilia made things difficult for me growing up, particularly in relation to my education. I went through the normal education system but there was no support for someone with an illness like mine with a nickname 'blood-vessel'. The rough and tumble of the Comprehensive School system (1977-1982) meant knocks were inevitable. Consequently, I received Factor VIII on a fairly regular basis. This resulted in 30% attendance overall and during my Ordinary Level qualifications, I spent 50% in class and ended my schooling with 6 GCE's.

6. Because I spent so much time off school, it was thought that it would be beneficial if I did my Advanced Level qualifications at Hereward College for the physically handicapped, which was residential, so if I had a bleed I could still attend lectures. It was challenging to accurately perform a titration in a wheelchair when I had a leg bleed.

7. Initially, I was treated at Birmingham Children's Hospital in Ladywoood with Cryoprecipitate. Then, in the 1970s, I was transferred over to Walsgrave Hospital and Coventry and Warwickshire Hospital, now known as University Hospitals Coventry and Warwickshire. This is where I started receiving Factor VIII. The Factor VIII was sourced from Coventry & Warwickshire Hospital through the college. The Haematology units at Walsgrave Hospital and Coventry and Warwickshire Hospital functioned as a single department. The senior haematologist was named Professor Neville Shinton, the junior haematologist Dr M. Strevens, and the haematology nurse Sister Christine Titley.

8. When I was young, my mum would be given a bottle of Factor VIII to mix with sterilised water for when I had a bleed. The doctors preferred Armour's Factor VIII from America to the British Factor VIII because it mixed better and was in better supply. However, mum did not want me to have the American Factor VIII. She believed that blood given for altruistic reasons would be safer than blood that people were paid to give. Although the medical professionals never told us about the risks associated with using Factor VIII, it was in the news at the time that British blood was safer. I also remember hearing that the Blood Products Laboratory needed to be enlarged in order to become self-sufficient. However, Margaret Thatcher's Government wasn't prepared to pay for this and after the event, they refused to acknowledge it, leaving us to die off and losing any chance to learn from it.

9. In light of all this, mum asked one of the lab technicians, Mr Lavington, if I could continue receiving British Factor VIII instead of the American

product. He said that he would try to keep me on British Factor VIII and for the most part, he did. However, I am not sure what type of Factor VIII I was given during periods when I was admitted to hospital, as they could not guarantee that they would provide me with British product. My mum approached this subject with one of the doctors but was told that they "couldn't give special treatment to one teenager".

10. In 1985 when I was 20 years old, I started my Higher National Diploma in Chemistry at Kingston Polytechnic, now Kingston University. In Autumn of the same year, I had a spontaneous bleed in my right lower leg which lasted two weeks so I went to Kingston Hospital for treatment. I had a vial of British Factor VIII with me; however, I was told that this wasn't enough to stop the bleed and that they would have to give me some more Factor VIII at Kingston Hospital. This was a one-off treatment during my time at Kingston and the name of the doctor who treated me along with the origins of the Factor VIII administered are unknown. However, it was the last treatment I received before my HIV status was confirmed 14 months later.

11. Due to my regular use of Factor VIII, I was tested on a regular basis for various things such as liver function. However, I was not informed that I was being tested for HIV. They must have added this in alongside the other tests without telling me.

12. Around Christmas 1986, Professor Shinton called me into the hospital as he said he had something he needed to tell me. I went in and I was given the news that I was HIV positive. Professor Shinton didn't really give me any more information about the infection at that point. He just explained to me that they had been testing me for HIV for a while and that this was the first time I had returned a positive result. He said my previous test in August 1986 had been negative. I had no idea that I was being tested at the time.

13. I suspect that the doctors may have been lying about the negative result in August 1986. The last jab I could have been infected from was the one I received at Kingston Hospital in Autumn 1985, given this was the last time I received Factor VIII before my HIV diagnosis. Even if I had been infected on this last occasion, it should have shown up in the test I received in August 1986. I suppose it could have been a false negative; however, I am concerned that the doctors may have decided to keep things under their hat until they had figured out what to do.

14. I was retested in January 1987, straight after Christmas, and it was confirmed that I had HIV. Again, the doctors gave me limited information about HIV and what it meant for my future. I recall that initially Dr Shinton gave me the impression that the infection was just an inoculation against the effects of the virus: a similar effect as inoculating against polio by giving the patient an inert version of the virus. I suspect he may have just wanted to calm me down.

15. The treatment vector for the HIV infection could have occurred prior to my studies at Kingston Polytechnic. It could have conceivably been whilst I was studying for my A-levels at Hereward College one to two years before, in which case the source of the Factor VIII was at the Coventry Hospitals. This is the same source of the Factor VIII that GRO-C other haemophiliacs within my extended family received. Out of the GRO-C have become infected with HIV.

16. Around the time of my diagnosis, I feel I was not given adequate information to understand and manage the infection. I was simply left to my own devices. I was also not given any information about the risk of transmission. Again, I was left to find this out for myself. For example, it was only from watching the news that I found out I could be sectioned if I have sex with someone without telling them I have HIV.

17. After the completion of my A-Levels, the frequency of Factor VIII injections steadily decreased, though I still continued to receive it when

necessary. However, after my HIV diagnosis the source of the Factor VIII was actively questioned, and product harvested from blood donors was rejected in favour of genetically modified product.

18. At some stage after being diagnosed with HIV, I found out I had also contracted Hepatitis C. I was told about this at Walsgrave Hospital; however, I can't remember exactly when this would have been.

19. Around 1995 when I was ill from my HIV infection, I found out that I had also contracted Hepatitis B. I was in Heartlands Hospital when I was diagnosed and had turned yellow from the jaundice.

20. I cleared both Hepatitis C and B relatively quickly. I was not given any treatment for either of these infections.

Section 3. Other Infections

21. As far as I am aware, I did not contract any infections other than HIV, Hepatitis B and Hepatitis C. However, I have been told that there is a possibility I could have also been infected with variant Creutzfeldt-Jakob disease ("vCJD") as a result of the blood products I received.

22. I found out about the risk of vCJD through a letter sent to me by Dr O Chapman at University Hospitals Coventry and Warwickshire NHS Trust in July 2009. I produce a true copy of this letter as **Exhibit WITN0816002.** It merely warned me about the risk that I could have vCJD and gave no contact information for support services or medical professionals I could discuss this news with, other than stating I could contact my haemophilia centre.

23. I was given the option to take a test assessing whether there was a possibility I would get dementia later in life. I cannot recall what type of dementia they were testing for but it may have been related to the HIV. I decided not to get tested. It would have just been a further thing to

worry about on top of everything else and so I decided I would rather not know.

Section 4. Consent

24. As far as I am aware, I have never been treated without my knowledge or consent. However, I do feel that I should have been given more information about the risks associated with the lack of quality control for Factor VIII sourced from the American blood banks. I was given the impression that Factor VIII was safe and that there were minimal to no risks. At the time, it was routine treatment for people with haemophilia so I didn't think much about what was in it. I feel the risks should have been properly explained to me so I could make an informed decision about whether to use it.

25. As I have already mentioned, I was not informed that I was being tested for HIV until I was diagnosed. I think the doctors were also testing for hepatitis at the same time but, again, I wasn't informed of this until I was told I had hepatitis. I frequently had routine tests for various things, such as liver function; however, I was often not told exactly what I was being tested for, so I didn't notice that they had slotted in further tests.

26. I am also concerned that the doctors may have decided not to inform me straight away when I first tested positive for HIV. As I have already stated, I believe it is likely that I actually returned a positive result earlier than the doctors claimed.

Section 5. Impact

27. Being infected with HIV has had a significant impact on my physical and mental health, my education, my ability to pursue a career, and my relationships. It has stopped me from being able to lead a life similar to those of my peers.

28. The impact on my physical health was fairly gradual at the beginning. My CD4 count continued to fall and by 1992, it had become so low that yeast had started developing on my skin, causing it to flake and bleed. The same year, I was put on the antiviral AZT. However, my health deteriorated further over the next few years as my CD4 count continued to drop. I was rapidly losing weight and suffered from terrible fevers.

29. By 1995, nothing had shifted and I had a permanent fever. One day, my mum came home at lunch to check on me and found me shaking, even though I was still in my pyjamas with a blanket on against the radiator. I was taken to Walsgrave Hospital but the doctors did not know what to do. We were informed by Dr Strevens that I was probably dying. He essentially washed his hands of me, stating that I was "too ill" so it was not worth me trying other antivirals. It made me angry because others, such as drug addicts, were receiving these antivirals whilst I was not.

30. Dr Strevens kept dragging his feet, stating that he was a haematologist and couldn't be an expert in everything. I understood this. However, I should have been referred earlier to someone who was an expert in HIV. This was especially important with something as serious as this; it was a matter of life or death.

31. It was not until Christmas 1996 that I was finally referred to an HIV specialist at the 'Tropical Diseases' department of Heartlands Hospital. Shortly before I was referred, I had a visit from the head nurse of the haematology department at Walsgrave Hospital, GRO-D. She came to give me an injection and I believe she may have noticed a Christmas card on the table from our local MP. My parents and I found it interesting that I was finally referred to a specialist very soon after this.

32. When I was first referred to Heartlands, I was extremely unwell. I was in a wheelchair at this point as I couldn't walk. My weight had also dropped to 45kg and my temperature was permanently at 40 degrees. My only relief was maximum daily doses of Paracetamol to drop my temperature constantly.

33. At Heartlands, I was placed under the care of Dr David White, an HIV specialist. As soon as I was wheeled in, he said I should have been referred to him twelve months ago. Initially, my health started to deteriorate further and I spent a month in Heartlands Hospital. My CD4 count at this time was 'statistically negative'. It was quite difficult for Dr White to figure out what was going on with me and what the solution was.

34. My low CD4 count opened me up to all sorts of infections because my immune system was so depressed. I was diagnosed with Mycobacterium avium-intracellulare infection (MAI). I was put on an antibiotic called Amikacin to try to get rid of the infection but nothing was working. The antibiotics also had side effects, including vertigo that was so bad I couldn't walk straight.

35. During this period I also had uveitis, an eye infection, as a result of my CD4 count being low. I also suffered from nausea and vomiting.

36. In 1995 whilst I was in hospital, I went yellow due to jaundice. This is when I was diagnosed with Hepatitis B. At some point, although I can't remember when, I was also diagnosed with Hepatitis C. Luckily, it did not develop to cirrhosis of the liver and it has had no long-term physical impact on me.

37. By 1997, the AZT still had not helped me at all so I was taken off it and was given a mix of standard antivirals and protease-inhibitors. I am still on this format of antivirals now, although they have tweaked the dosage a number of times since then.

38. The main side effect of the antiviral drugs was that I had loose bowels and was on the toilet all the time. I was prescribed Imodium to control this; however, this led to huge bloating. I also suffered from blood poisoning and I feel as though this could have been a complication of the Imodium. The blood poisoning caused me to be totally out of it and I had to spend four weeks in hospital. One day, I started walking down the ward saying that I had "had enough" and that I was going home. I shouted that I was "fed up of this damn dog", referring to the hospital bag that was trailing behind me. In my mind I thought I was in a pub on the south coast, not in a hospital in Birmingham.

39. One of the antivirals also made me lose a lot of the fat deposits on my face. The effects of this have been permanent.

40. By August 1997, the antivirals still weren't working properly and I was at my most unwell. I spoke to the matron of the ward about this and I asked to be put on something else. As a result, I was put on steroids for about a month or two and, fortunately, my health improved.

41. Although I started feeling better when I was put on steroids, I soon developed Osteoporosis. I believe this was a side effect of the steroids but it may have also been due to my constant high temperature and poor appetite. I remember being in absolute agony one evening after having been out in the car. I had not done anything physical and yet I later found out that I had crushed two vertebrae. I remember I wasn't even able to watch a comedy programme because even laughing was so painful. The impact of this has been permanent and it has caused me to be two inches shorter than I was previously. I now also have only a tingling sensation, rather than feeling, in my feet.

42. From 1998 onwards, I started coming out of the infection period. My CD4 count started to rise and reached 250.

43. Although my health continued to improve for a few years, by 2004 my CD4 count started to tail off again. Dr White could not work out why. I ended up being referred to immunology and then a hepatologist, but no one could pinpoint what was wrong.

44. Eventually, in 2018, Dr White came across a very rare condition called Protein Losing Enteropathy ("PLE") in a journal article. I was tested in the summer of 2018 and saw a gastroenterologist in September of the same year. He diagnosed me with PLE and said I was the third person he had ever seen with this condition. Dr White thinks it could be related to the HIV but the doctors are still learning about it themselves. As a result of this condition, my CD4 count, lymphocytes and albumin levels have all gone down across the board. The last time I was tested, my CD4 count was 78 and it is continuing to drop slowly.

45. One of the effects of my PLE is that my lymphatic system leaks into my gut. At the moment, I am going through various tests to find out where the site of the leak is. I may need to have a piece of my gut removed later this year to remedy this. I am therefore having regular appointments about this at the moment. It is a further complication on top of everything else.

46. In addition to all these physical symptoms, my mental health has also suffered as a result of my infection. The first couple of years after my diagnosis were particularly difficult. Mentally, I fell apart realising the ramifications of my infection and I started suffering from depression and anxiety. I found it very difficult to get my mind around the fact that I wouldn't be able to do certain things with my life. I always assumed that I would follow a similar path to my parents and so it was difficult when I realised I had to completely rethink this. Now, I just try to get through each day as best I can.

47. Having HIV has also had a significant impact on my social, family and private life. You could say that my life hasn't changed since I was

nineteen. I have managed to buy my own house; however, those around me, such as my brothers and friends, have all moved on in relationships. They have married and had children so they have their own families. I have no family aside from my parents, no next generation. It has made things particularly difficult because in many ways, I have had to come to terms with my HIV infection on my own.

48. My infection has also had a significant impact on my parents. My mum had to retire early to care for me when I was extremely ill. They have supported me through my illness and we try to roll with the bad times as much as we can as a group. We have had to come to a sort of equilibrium despite everything that has happened.

49. My social life was impacted early on in my illness. I had moved about whilst I was studying but had to return to my parents house when I became ill. I was hardly able to leave the house during this period. It made it difficult for me to see family and friends. Mum would check on me during her lunch break everyday. My routine would be to have breakfast, get dressed, go downstairs, watch television and sleep. It wasn't really a proper life.

50. I have also struggled with the stigma associated with HIV. There is a lot of prejudice and this is only spurred on by things such as the adverts produced by Margaret Thatcher's government in the 1980s, which were intended to shock people and make them fearful of HIV. Sometimes I feel as if I ought to carry a bell and shout "unclean". Mentally, it takes its toll on you. Things have quietened down these days but it I am still careful about who I tell about my infection.

51. My education and career have also been greatly impacted by having HIV. When I was diagnosed, I was in the middle of my Higher National Diploma in Chemistry at Kingston Polytechnic, which I finished in 1987.

52. In 1987, I started working in agrochemical research. This was when I was feeling most down about my HIV, as I was still attempting to come to terms with my diagnosis. I told my work that I had started feeling down about the future and, physically, I became very ill. I fell to pieces really. I was not sacked but it was made clear that I wasn't going anywhere in this job, and I was essentially pushed out.

53. I then started a new job running a Nuclear Magnetic Resonance ("NMR") Spectrometer. In 1989, I left this job on my own accord because it wasn't going anywhere.

54. In October 1989, I went back to Kingston Polytechnic for a further two years to get a Bachelor of Science in Chemistry. I completed this degree in 1991. However, the impact of the infection on my mental health made it difficult to engage at university. I simply had to power my way through things as much as I could.

55. In 1991, after I completed my Bachelor of Science, I moved to Glasgow where I started a Masters degree. After completing this in 1992, I started looking for a job but by then, my health had started to deteriorate.

56. My career was stopped before it had even got started. As my health got worse, I had to stop applying for jobs. I have not worked since 1989.

57. As a result of not being able to work, my knowledge of chemistry has declined because I don't have an opportunity to use it. It is difficult to remember what I learnt so many years ago when I am not putting things into practice.

58. Given my infection has stopped me from working, I have also been impacted financially. I was never able to pursue the chemistry-related career I could have had, probably in middle management. Because of

this, I have always had to be careful with my money and make sure that the pennies are there to do the things I want to do. I invested the money I received from the trusts and schemes and was eventually able to buy a house.

59. The Department of Work and Pensions ("DWP") are not geared up to my situation at all. I am unable to work due to my HIV. Given I am often falling ill, I can't guarantee I will be able to work or turn up. However, the DWP are not very understanding and they insist that I actively look for jobs, despite my consultant stating that I am unfit for work.

60. The DWP calls me in every six years, sometimes more frequently, to assess whether I am eligible for disability benefits. They aren't interested in my medical history at all. They only care about whether I can dress myself, walk a certain distance, go to the toilet and so forth.

61. Whenever I go in for a medical assessment, I have to go in, fill out a form, give documentary evidence, and have a medical. I had a medical assessment six years ago and again last year. On both occasions, they decided to stop my sickness benefit, which is called the Employment and Support Allowance. I appealed this each time and won. However, while I was in the process of appealing these decisions, I had to go on the Job Seekers Allowance to get by, which meant I was expected to be looking for a job fulltime. I am back on the Employment and Support Allowance now, but I am worried that this cycle will happen again next time I need to complete a medical assessment.

62. The DWP also brought me in when I bought a house, despite the fact it was my own frugality that allowed me buy it. When something like this happens, they do a trawling exercise, which is stressful for me and takes a long time to sort out. This constant justification of my situation and dealing with the bureaucracy of the system wears me down all the time.

Section 6. Treatment/Care/Support

63. I am very unhappy with the care I received at Walsgrave Hospital and Coventry and Warwickshire Hospital. We had to do a lot of arm-twisting before Dr Strevens finally referred me on to an HIV specialist. I didn't find Dr Strevens very professional at all and he could have been more proactive in terms of getting me proper treatment. It felt as though he didn't care anymore because he was approaching retirement.

64. I have no complaints about Heartlands Hospital as there were no more difficulties or obstacles in relation to my treatment once I had been referred to them. The only issue was trying to work out why my CD4 count kept dropping, but Dr White was very persistent with this and tried everything he could. I don't think I would have lived through all of this had Dr White not persevered. I am very happy with the care I have received from him. He has said that I was his best patient because I was so ill and yet I made such a good recovery.

65. However, the communication between Heartlands and Coventry was tenuous at times. There was no interface between the two. Heartlands often did not get anything back from Coventry, despite them sending reports. About a year ago, Walsgrave Hospital decided to transfer me to Queen Elizabeth Hospital in Birmingham and this is where I receive my care for my haemophilia now. I still attend Heartlands Hospital for my HIV infection.

66. I have never been offered any counselling or psychological support to help me deal with my infection. At Coventry and Warwickshire Hospital and Walsgrave Hospital, there wasn't anything at all in terms of support. When I was first diagnosed I was not offered anything. It was "sink or swim". At Heartlands, although I was not specifically offered support, everything you could need is on site so if I needed any help I could just ask.

67. My parents went to a support group for people in the same situation as myself, which I believe was run by the Haemophilia Society and had nothing to do with the NHS. My parents said it was very useful to meet other people in the same situation; however, they thought the counsellor was useless.

Section 7. Financial Assistance

68. I have received financial assistance through the Macfarlane Trust and from Armour Pharmaceuticals. I piggybacked onto a class action litigating for those who had been infected with HIV. I can't remember the name of the firm of solicitors I instructed; however, it was the solicitors, not the doctors, who told me about the possibility of compensation.

69. Around 1989, I received the first payment of £20,000 from the British Government through the Macfarlane Trust. I can't remember the exact date I received the payment but it was shortly after I had been diagnosed. Soon after, around 1990, I received a further £20,000 as part of the final settlement of the class action. However, I had to sign a contract to say that I would take no further legal action. I also received a further £40,000 from Armour Pharmaceuticals in around 1991.

70. In total, I received £80,000 in lump-sum payments, and I invested all of it. When I was ill, I lived with my parents and didn't spend anything. The money built up slowly and I was eventually able to buy my house.

71. After receiving the lump sum payments, I also received monthly payments through the Macfarlane Trust. This began at less than £300 per month. These payments are now administered through the England Infected Blood Support Scheme ("EIBSS"). I was receiving approximately £2,000 per month, which included an income top up

payment of around £479 per month given I do not work. However, they recently increased the payments I receive. I cannot recall exactly how much I receive now but I do know that the increase was backdated to April. This money is important because it allows me to have a choice about the food I eat and is necessary for me to pay for heating.

72. I found the application process through EIBSS more difficult than the one through the Macfarlane Trust. It is very tedious having to constantly fill out forms. Repeating myself and constantly having to justify the money I am receiving also wears me down, particularly with the DWP on my back. It's a case of constantly jumping through hoops to receive enough money to live.

73. I was not able to receive anything from the Skipton Fund because I had cleared the Hepatitis C by the time the fund was created.

74. I do not feel that the amount of financial support that has been provided is sufficient. It is rather poor given what I have been through and considering what I could have earnt as a scientist had I been well enough to work.

Section 8. Other Issues

75. I have never been involved in any previous inquiries or campaigns. I am hoping that this Inquiry may lead to better financial support for people in my situation. However, I also think it is important for us to find out where the skeletons lie.

76. I am angry that Factor VIII continued to be used after the risks were known and it is frustrating to know that situations such as mine could have been avoided. I therefore hope that this Inquiry will be able to give us answers, including why this has happened, when the Government first knew the blood products were contaminated, and why they

continued to use it once the risks were known. I hope that this Inquiry can expose what the Government has tried to keep hidden for so long.

Statement of Truth

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

Signed GRO-C

Dated 27/7/19