Witness Name: Daniel Poole
Statement No.: WITN0657001
Dated: 7 February 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF DANIEL POOLE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 28 November 2018.

I, Daniel Poole, will say as follows: -

Section 1. Introduction

1. My name is Daniel Aaron POOLE. My date of birth is GRO-C 1977. My address is known to the Inquiry. I am a married man, with a nine-year-old child, living with my family in Hertfordshire. I am in full time employment.

2. I was born at The University College Hospital, London (UCH). Shortly after my birth, I was given an injection of Vitamin K in my leg. Almost immediately, I reacted to the injection – my whole leg from my hip to my foot bruised. This resulted in tests being carried out, and by the time I was a mere eighteen hours old, I had been diagnosed as having Haemophilia.

3. In this statement I intend to speak about my Haemophilia and my subsequent infection with Hepatitis. In particular, the nature of my illness,

how the illness affected me, the treatment received and the impact it had on me, my family, and our lives together.

Section 2. How Infected

4. It is my belief that I was infected with nonA, nonB Hepatitis now known as Hepatitis C (HCV) after receiving a contaminated Armour branded factor VIII blood-clotting product. At the time, my mother knew there was something wrong because after receiving one particular injection my stomach expanded, my skin colour changed and I was unwell for several weeks.

5. I started on Factor VIII when I was in Junior School. So I believe I was infected before 1986 when I was a young child.

6. I was diagnosed with HCV after a routine bi-annual consultation at Great Ormond Street Hospital (GOSH) in 1988 when I was 11 years old. I knew very little or nothing about HCV. At the time, that was a good thing because I did not understand it.

7. While at GOSH I received various tests. I now know these were for HIV. I understand that my parents were told that all haemophiliacs were being tested for HIV. I was not told about what tests were carried out and even if I had, given my age, it would have gone over my head. There was often discussion in the corridors and closed office doors with my parents. I remember my parents discussing medical things with me. This was mainly as a result of press coverage about HIV and AIDS. There was no written consent but this might have been done verbally with my parents.

8. I continued to have bi-annual checks. Whilst under the care of St Thomas' I remember having a number of PET scans to determine the damage HCV had done to my liver. It was known to cause damage at the time but they didn't know how much. The results showed some

scarring but nothing significant at the time. At the time there was no treatment available so all they could do was monitor my condition.

Background

Haemophilia

9. Even though I was diagnosed with haemophilia A shortly after birth I did not experience any major symptoms for at least a year. When I did, it was usually bleeds in my knees, ankles and bottom. This often was as a result of general bumps that all toddlers experience and some spontaneous bleeding.

10. The only available treatment at the time was to go to GOSH. Get in the car and go. Luckily my father had his own business and was able to accommodate the frequent trips to the hospital. Naturally, both my parent's lifestyles and business' were impacted by these trips.

11. Home treatment started for me in 1983-1984 when I was 6/7. This was a life-changing event. I no longer needed to be rushed to GOSH for treatment. Prior to this, Cyroprecipitate was the only medication available to me but when concentrate factor became available my father was trained to administer this into a vein. My mother couldn't come round to doing the treatment and my father became my primary carer.

12. In 1986-87 my medication moved from Cyroprecipitate to Factor VIII. I was 9-10. Until then, we hadn't been able to take 'normal' holidays like other families.

13. I had one bleeding incident where I was treated with Factor VIII but the product failed to stop the bleeding. I went to GOSH and was given a heat-treated Blood Products Laboratory (Elstree) product (BPL).

Once I received this treatment the bleeding stopped and the pain went down. This product then became my main treatment.

School

14. I was never sent to any special schools as a result of my condition. Initially, I was sent to a pre-school playgroup that was attached to the synagogue in GRO-C. I went for a few hours during the day. I then moved onto a Private School.

15. I struggled through school and my parents arranged for me to see a specialist. After GOSH had assisted and a visit to a specialist for two weeks I was diagnosed with Dyslexia. I remember also going to GOSH for tests. Looking back these were probably IQ tests. At the time there was no pastoral care for dyslexia.

16. With my dyslexia Private School wasn't the right environment for me and I was faltering with my education. I then moved on to a state school. I liked this school.

17. Whilst the school had no treatment facilities for haemophilia they had a protocol in place should an incident occur; the school would phone my parents. Prophylaxis was not widely known about or available at the time.

18. I missed out on school trips and could never go to the school camps. I tried to keep as active as I could but would often bleed a lot so frequently missed school. I once missed school for three months after a bleed in my hip. This to led to traction treatment at GOSH however this consequently caused a dislocation of my hip. This left me severely isolated and I fell behind. There were no remedial classes to catch up with things that I missed. I do remember one after school lesson but I'm not sure if this was for me to catch up or find out how behind I was.

Social

19. I struggled to make friends at school and became very isolated on account of some of the very negative press articles about at the time. My parents enrolled me in the Sea Scouts and Jewish Lads' and Girls' Brigade (JLGB). I attended regular weekday evening activities and some summer clubs. I made some friends but not long lasting ones. I remember playing golf and archery in the summer holidays. I couldn't touch a football though as it caused regular bleeding in my ankles but played softball a lot. My mum wanted me to get out and do things; to lead a normal life. I still struggled to make friends – trust being my main barrier.

Section 3. Other Infections

20. I know there is a risk that I may have been exposed to Creutzfeldt-Jakob disease (CJD) but this is not something I want to discuss or think about. I believe I received a letter about it in recent years.

Section 5. Impact

School

21. Growing up with Haemophilia and HCV was difficult – I was very much on my own. School was horrendous; utter hell. I was an underachiever due to missing so much school and unfortunately targeted by bullies. My dyslexia compounded these problems. People would make comments all the time and I felt like I was everyone's target. I even took part in activities that a haemophiliac shouldn't, just to fit in. For example I tried to join in with card games that would

involve a persons hitting a pack of cards on your knuckles or trying to join in football at break time regardless of the bleeding consequences.

22. When I was in middle school there was a media frenzy around HIV/AIDS. These adverts put sheer fear into everyone. People believed they could catch HIV/AIDS through most activities; sharing a toilet seat using the same cutlery etc. There was massive Stigma. It was only when Princess Diana shook the hands of an AIDS patient that the paranoia around this started to change.

23. Everyone in school knew I was a Haemophilic. Students often associated my Haemophilia with these ads. A lot of parents asked their children to stay away from me and even asked the school for me to be removed fearing their children would catch HIV from me despite the fact that I was negative. It was extremely isolating. The best way to describe the atmosphere is the reaction you get when you have a cold. People know you have a cold, stay back and pull a face; being a haemophilic with HCV is a million times worse – imagine the reaction. I remember going to a close family friend's house for dinner. They threw the cutlery and plates that I had used into the bin. My immediate and extended family, however, remained supportive. I spent a lot of time with my cousins during my upbringing.

24. I had one friend at School; Richard. His dad was not comfortable with us being friends initially because of my condition. His mum was more supportive as she believed that I could not pass anything on. Richard would often come to my house for dinner on a Friday night and we spent most Saturday's doing things together.

25. My teachers were aware of my condition. My head teacher in High School, for example, would be quick to jump on violence of any kind. Generally, teachers were understanding and empathetic but some were rude. I remember one teacher at middle school who was very unpleasant, shouted at my parents at one open evening while

throwing my books at them. He said I wouldn't amount to anything. My head of year in middle and high school was interested in my Haemophilia and had a plan to deal with incidents.

26. Progressing through school, I was more aware of when I needed treatment – what causes bleeds. I could then try to control my condition more. I started cycling to school. During the last years of school the realms of Prophylaxis became more available.

27. I left school at 16 and started an apprenticeship in film and television lighting. It was a City and Guilds course in conjunction with the BBC. I didn't meet the criteria / grades to start the course but family contacts and an extra commitment to make up the shortfall in my grades managed to get me enrolled on the course. The course was for 4 years and I stayed on for a further 3 years post apprenticeship with my employer and started to move on to IT as a career.

28. Initially, I was bullied during the apprenticeship. Only the owner and very senior management knew about my condition. I was sometimes given the less exciting and hard manual tasks, my line manager at the time was very stuck in his ways and made life very difficult. A change in line management a few years later changed my fortunes.

HCV Treatment

29. During school my HCV was monitored but during my apprenticeship my Senior Registrar at the time, Mr Mark Smith, advised me that we needed to address it. I was 17 and the only treatment was by taking this product called Interferon. I remember being told that there was no guaranteed fix.

30. The discussion around whether to start treatment was completely verbal – I didn't receive any documentation. I felt I had enough information to make a call around starting treatment at the time. In

hindsight, no amount of information or paperwork could have prepared me for the side effects.

31. My parents were keen for me to start treatment – they didn't want to risk my life ending early. I was less eager to start and had reservations. I hardly had any physical side effects from HCV and I had concerns that I would sacrifice a large part of my life to a drug that may or may not work.

32. I started on Interferon in January 1996. It was self-administered and I would do subcutaneous injections, I cannot remember exactly how often and how much the dose was each week.

33. For the first dose I was instructed to take two Paracetamols, administer the injection and go to bed. It was a Friday when I administered my first dose. I remember it well. I woke up at around 2 am and felt bad – really bad. It was like I had the flu but I had an ache in every part of the body. Every time I administered the treatment it made me feel really ill. I struggled with my sleep so I would take the injection earlier in the evening to see if I could have the side effects while I was still awake and then sleep afterwards. This was the only way I could get any half decent sleep.

34. I had two core friends at that stage; Simon and Ben. In addition to my family they were both hugely supportive. They would adapt their weekends to accommodate my frequent mood swings and my symptoms. Interferon affected my mood greatly. My mood got dark very quickly. I had severe psychological issues – often thinking about suicide. I felt like I was looking up from a really deep hole: I remember thinking when will this end whilst sitting on Simon's bedroom floor on a Saturday morning sobbing. In hindsight this was probably depression. These mood swings and thoughts continued for 12 months while I was on Interferon.

35. I had some support from some very understanding people. While at college my head of course at the college had acquired cancer through asbestos. This made me feel comfortable to share the fact I had HCV and was on Interferon. His name was Russell and he really helped me through my college education at the time.

36. I started to have issues when I had to work on a Saturday while on the HCV treatment. I felt like death. The first four or five hours was like walking around with lead boots. My work environment was pretty intense and physical before the management changed. If I didn't work I would be ripped to shreds (metaphorically speaking). My Saturday afternoons and evenings were spent comatose after a Saturday at work.

37. Once the management changed I started to have more support. My new manager (Chris) adapted my work when I was feeling down. I would do less manual work and more activities where I could sit, for example, working in the repair office fixing lighting equipment. He was aware of my condition having been told by St Thomas' hospital with my consent. Senior management were also aware.

38. I had quarterly check ups when I was on Interferon (before this it was bi-annual). I was clear of HCV while on Interferon. Three months after stopping the treatment a routine follow-up test at St Thomas' showed that the HCV antibodies were back. The treatment had not worked. The news was broken to me by Mr Mark Smith as a matter of fact – the HCV had come back. He did not recommend the treatment be restarted. At this stage, I started to do a bit more research into HCV – typically by asking questions or finding whatever information I could from differing sources. Information was limited and there was not a definitive source to go to.

39. During and after the treatment I started to develop numbness in the bottom of the feet. This sensation would creep up to the bottom of my

knee. It was very uncomfortable. There were only two ways to get rid of it; either by walking it off or laying down. I still suffer from this and it has now moved to my fingers as well. I believe this is a side effect of Interferon. The other flu-like symptoms and the dark thoughts, however, went away after a period of 18 months post treatment.

40. When I was nearing the end of my apprenticeship a new consultant, Ms Savita Rangavajan, took over my haemophilia care at St Thomas from Mr Mark Smith. After a couple of years under her care she suggested that the HCV needed to be addressed. Given my experience with Interferon I was hesitant.

41. Separately, I went to see another doctor, Mr Wong, for an unrelated issue. Mr Wong had seen I had HCV in my medical records. In a very blunt and direct manner he told me that if this was not addressed and treated I would get cancer and die. I was shocked. I immediately made arrangements to see Savita. The treatment for HCV had changed. The treatment for HCV was now a combination therapy; Interferon was now supplemented by another drug called Ribavirin which was a pill.

42. I was worried about taking Interferon again. By chance I saw my previous consultant, Mr Iain Savage and we discussed it at length, and I eventually decided to go on the treatment. By the time I started this second round of treatment I had finished my apprenticeship and moved into IT – an area that I feel was better suited to me. Working Saturdays was rare and the only times I would do out of hours work was when there was a major IT upgrade. The work was less demanding and, therefore, I could manage the treatment better. I had developed coping strategies. Additionally, my friends were even more supportive as they had seen what I had been through during the first round of treatment and they really stepped up and tried to keep me in a better place. My family also were as always massively supportive and understanding.

43. I had the same side effects that I had previously experienced with Interferon, however, this time it was compounded with massive stomach problems.

44. I suffered from Irritable Bowel Syndrome (IBS) since I was 13. This was controlled through pills. I believe the Ribavirin caused these symptoms to be exacerbated.

45. I lost a lot of weight and had extreme mood swings again. This time round my low moods took longer to fizzle out. In fact, all the side effects took longer to go away.

46. The numbness I had experienced from the first round of treatment stayed. This time the symptoms took up to 24 hours to completely disappear and I continue to suffer from this today. I have also ended up with a neurological condition in my left leg and calf where I experience a dulled sensation. I believe this is a permanent side effect of Interferon.

47. After the first month on the combination therapy (starting February 2001) I was clear of HCV. At the time there was not enough data to confirm whether it was completely gone and I stayed on the treatment for six months. This led to me having very difficult conversations with my girlfriend at the time about what HCV was and the potential issues around it.

48. Looking back, while the HCV infection is gone I feel that those infected need more information about the impacts of this treatment. Although the issues HCV causes leave very little options anyway.

Financial Impacts

49. I have a strong work ethic, something my whole family has. I have been in work since I started the apprenticeship. I now work for an IT company as a Sales Engineer. The company allows me to work flexibly on top of allowing me to use a taxi where appropriate, for example, when my ankles or joints hurt. It also has a generous sick policy, which I used for the first time recently following surgery on my right ankle. I feel I have been lucky with this otherwise I would have potentially incurred financial problems.

50. I have previously been denied insurance services because of my HCV. I struggled to obtain life insurance on the open market. My current employer insures me but limited on total value because of the past infection and Haemophilia. I would have eventually liked to become self-employed but the lack of insurance services has been a barrier.

51. I have a critical illness policy that I am unable to change; at the time they didn't ask me about HCV. Insurers now always ask whether you have previously had HCV and as such I am unable to switch provider even though there are cheaper deals available.

52. Generally, even though I have cleared my HCV my insurance premiums increase as soon as I mention I previously had this infection. I have managed to mitigate some issues by taking joint products with my wife Susan.

Section 6. Treatment/Care/Support

53. The HCV made it difficult to find a good dentist. I declared my HCV to one dentist and he wouldn't touch me. I felt like a leper even though I knew I could not transmit the infection. I now go to a dentist that has knowledge of my history and Haemophilia.

54. I have not received any counselling or psychological support. It is only now that I'm hearing about the options once the inquiry commenced.

55. I was told about the Red Cross scheme and was given the contact card / information.

Section 7. Financial Assistance

56. I currently receive a Personal Independence Payment. I was previously on Disability Living Allowance.

57. Around 1987 I applied for a stage 1 payment from the Skipton fund. At the time I was still infected with HCV. The communication from the fund was poor. I was not kept updated. After a long delay I received a one off cheque. I do not remember signing any legal waivers. No pharmaceutical companies have approached me.

58. I received a phone call this year (2018) from the Skipton fund encouraging me to apply for a stage 2 payment. The process was very bureaucratic and after going through all the questions including ones relating to my mental health and the massive effort from St Thomas' haemophilia team to complete their part of the documentation I got a rejection letter. This was very frustrating as I was encouraged to apply by the scheme. I believe there should have been a better process.

Section 8. Other Issues

59. A few years ago a nurse who worked at GOSH recognised my father after bumping into him on an off chance. She told him that they were treating 103 patients including me as a child. They tested everyone

for HIV. The nurse told him that 100 of these patients have now passed away.

60. Around 1983 when I was 5-6 my parents started a charity called Factor VIII. A lot of the money that was raised was used to fund research into haemophilia and treatments.

61. The charity was registered and run from home and it ran up until I was around 14. I remember the charity holding big events. One was held at Honda in GRO-C and big names such as M&S attended.

Statement of Truth

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

Signed GRO-C

Dated 7/2/2019