Witness Name: Andrew Evans
Statement No: WITN1213001
Exhibits: WITN1213002-4
Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ANDREW EVANS

I, Andrew Evans will say as follows:-

Section 1. Introduction

1. My name is Andrew Evans, DOB GRO-C 1977 and I live at GRO-C GRO-C, Worcestershire, GRO-C with my wife and three children.

2. I was infected with HIV and Hepatitis C through contaminated blood products.

3. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How infected

4. I was diagnosed with severe Haemophilia A on 17.01.1978.

5. I had fairly regular treatment when I was younger and I was part of the first cohort who were taught to self administer at home. I started injecting myself when I was just 3 years and 10 months old. I was mainly treated at home but

there were some hospital stays also. I was treated at Birmingham Children's Hospital under Dr Frank Hill.

6. I didn't bleed as much as some haemophiliacs. Although I have severe haemophilia, I haven't suffered from problems with my joints; when I do bleed it tends to just be soft tissue bleeds.

7. I was tested for Hepatitis B on numerous occasions from 1979. I first tested positive in 1981. My medical records show that I was also tested for Hepatitis A and a whole host of other viruses in 1981. There is now shown to me marked **WITN1213002** a copy of the Viral Complement Fixation Test results which were carried out at that time.

8. My father had been made aware of a potential risk with Factor VIII when reading the New Scientist magazine in or around 1982. Shortly after this, my parents were called to Birmingham Children's Hospital along with other parents of haemophiliacs for a meeting. My mother raised my parents' concerns at the meeting, and she was told that there was more chance of me getting arthritis through non-treatment than getting AIDS through treatment.

9. Dr Hill told my parents that I was HIV positive in 1985. They were called in for a clinic appointment, and were not even aware that I had been tested. I do not remember much about the time of my infection as I was so young.

10. I now see from my medical records that my first positive HIV test result is dated 1983. There is now shown to me marked **WITN1213003** a copy of that result.

11. My Mum told me that I was HIV positive in 1989 when I was about 12 years old. We went for a drive and she pulled over to the side of a country lane, which I remember thinking was strange. She asked if I was aware that there was a problem with haemophilia blood and if I knew what HIV was. I had a rough understanding as I had seen the tombstone adverts on TV. She then told me that I had HIV and they had been running tests at the haemophilia

centre which showed that my CD4 count was dropping, so there was a chance I would have to start treatment soon.

12. When my Mum told me the news I just said that I would have to become a doctor or a researcher so I could cure myself; I could see how upset she was and I just wanted to make it easier for her.

13. I had no idea that I had also been infected with Hepatitis C until a flippant comment was made by Dr Wilde when I was having a blood test. He said 'oh and we must do a genotype test on your Hepatitis C as well'. He obviously assumed that I had known about it considering the way he said it to me. I was too shocked to say anything and we never really had a conversation about it. I blocked the Hepatitis C from my mind because I was so worried about the HIV that I didn't even have time to worry about it. I cannot recall when this conversation took place but I note from my records that I first tested positive for Hepatitis C on 08.03.1994 and that there is no reference to any earlier test.

Section 3. Other Infections

14. I had a letter telling me that I had been exposed to vCJD, and then a retraction letter telling me that I was no longer at risk.

15. I received a lot of phone calls the day that letter came out from members of Tainted Blood. There was a lot of media around BSE at the time and it was very frightening for everyone.

Section 4. Consent

16. Neither my parents or I had any knowledge that I had been tested for HIV or Hepatitis C and therefore could not have consented to these tests. I don't believe that they were told about the other viral testing either.

17. I believe I was tested for the purposes of research particularly given the number of viral tests referred to in 1981.

18. I believe I should have been tested for Hepatitis C earlier than 1994 given the state of knowledge about the disease in 1990/1991.

Section 5. Impact of the Infection

19. I first started my AZT treatment in August 1989 and I was put on a ridiculously high dose which made me feel extremely ill. I remember one day I was sick on the coach to school, some of which went over my class-mates sitting next to me. I was so embarrassed.

20. The progression of my HIV is set out in the letter attached at exhibit **WITN1213004.**

21. They started to add drugs like DDI into my medication and lowered the dose of AZT, which allowed me to get through the rest of school without too many side effects. I finished school and did reasonably well in my GCSEs, however there is no doubt in my mind that I would have done much better at school if it were not for my infection.

22. I dated a girl at school for a few months and we started to discuss sleeping with each other. I think I was spoken to by my parents about transmission and so I understood that it was sexually transmittable. I had to tell the girl about my infection and that caused the immediate breakdown of our relationship. That was a real blow for me and put me off relationships for a decade as I didn't think anyone would want to be with someone with HIV.

23. I had told my best friend at school about my infection. He was very good about it and would visit me when I was ill, however when I made a recovery he soon left the scene. I think he had been preparing himself for me to die and couldn't really get his head around the fact that I hadn't.

24. One of my old school friends later told me there had been an assembly held where they told all of sixth form that I had AIDS and was going to die. I don't know how true this is, but it seems like a very strange thing for them to do.

25. I signed up to stay on at school to go to sixth form but I then became very ill. At 16 years old, I had a fungal infection at the back of my throat and my CD4 count was under 200, which technically meant that I had full blown AIDS. I was regularly physically sick and I would wake up in the middle of the night sweating. I was taken to hospital in an ambulance many times where in each instance I stayed for a couple of weeks on intravenous antibiotics, and they sometimes gave me medication that I was allergic to which made everything worse. I gradually had to drop my subjects as I felt so far behind in college. I was always either in hospital or recovering from a stay in hospital.

26. I had chronic chest infections, sinusitis and several ENT-type conditions. I became allergic to Septrin which was the prophylaxis for Pneumocystis Pneumonia (PCP). They then tried me on Dapsone which was a leprosy drug, before they then put me on Thalidomide and then a Pentamidine inhaler. When I took Penatmidine I had to be on my own in a sealed room with a hosepipe going out of the window. Nurses weren't allowed in because the stuff was so toxic, but we would be breathing it in for up to half an hour at a time.

27. I was forced to use a wheelchair as I was so weak. It was one of the things that bothered me most because although I knew I wouldn't survive my illness, the wheelchair took away my mobility and any independence. I was fed through a naso-gastric tube as I couldn't keep anything down. I didn't want to wear the tube as I wanted to look as normal as possible, even if I was in a wheelchair. I rebelled against it at one point. My Mum then went to have a discussion with the doctor, and after she said that I could take the tube out but I wouldn't survive for much longer. The next day I kept the tube in. It was the wake up call I needed.

28. Dr Hill hadn't told me much about prognosis and life expectancy but my parents were told on more than one occasion that my next infection would probably be my last. I had no immune system and my CD4 count was down to zero. My neutrophils were destroyed and I needed injections every night. I was on Sandoglobulin infusions to try and boost my white cell count.

29. My hip bones crumbled away and I've had two hip replacements as a result of the high dose steroids that I was prescribed. My treating doctors tried drilling out the bone to see if fresh bone would grow and whilst it was not growing they gave me a huge plate hooked up to a box to sleep on to stimulate bone growth. This didn't work either. I am currently able to walk without a stick but my hip replacements are going to need revisions in the future.

30. I was still at the Children's Hospital by age 20 as for some reason they didn't want to let me go. By then it was like a second home to me. New medication started to become available and I was told that I would have to move to the Queen Elizabeth Hospital (QEH), Birmingham, to receive it. It was tough moving hospital as I had spent so much time with the staff at the Children's Hospital.

31. Dr Wilde moved me onto 3TC and I gradually started to see some improvements in my CD4 count. He then put me on protease inhibitors which continued to help (despite causing side effects such as brain fog, nausea, headaches and ingrown toenails), and then I was moved onto Individir.

32. I was at home one weekend in the late 1990's when I started to feel really strange. I was dizzy and had pains all down my left side. I would stand up and then blacking out. My Mum took me into the QEH and Dr Wilde took one look at me and said I was fine and could go home. I went back to the hospital that night as my left side of the body was spasming. They said I was exhibiting stroke-like symptoms but they didn't think it was a stroke. They still aren't entirely sure what happened to me, but it took a month to regain any strength in my hand and left side of my body, and my left hand is still very weak and has little feeling to this day.

33. My health started to level out in 1999/2000. The most formative years of my life had been spent in a hospital. All of my friends had moved on to jobs or to university, and I had no idea what to do with my life. The plan when I was at school was for me to go to university and do something to do with computer programming, so I signed up for a course with the Open University. Although I never ended up completing the diploma, I taught myself a lot. I found distance learning very isolating.

34. I then started some tiny businesses where I would print business cards at home and offer technical support for people's PCs. It would only be a couple of jobs a month for £10-£20 and I was still living at home.

35. I met someone in an online chatroom in America who had thalassemia. She had been infected with Hepatitis C and HIV through blood transfusions also. I flew over there to see her and we spent 14 months together. I went there in February 2002 and she died in April 2003. Two weeks after she died I received a call from my Mum to tell me that my Dad had died, so I had to go back to the UK. As I had overstayed on my American visa they wouldn't let me back over there, so I was never able to go back and make sure her family were okay.

36. When I came back from America in 2003 I started doing bits of IT work for the MacFarlane Trust. When Martin Harvey joined he wanted someone to improve their website and IT system. We created the bulletin board on the website that became like a chatroom for members. I started to get to know a few people through that and decided to set up Tainted Blood in 2006. We had a bit of a media run so there were clips and newspaper cuttings that we had nowhere to store, which is why I created the Tainted Blood website as a way to store them. We then started to create a timeline of events and it all snowballed into what Tainted Blood is today.

37. I now do web-development with another infected haemophiliac. I became self employed out of necessity as no one would have given me a job with no real education or experience. Being self-employed also allows me to fit my

working life around hospital appointments and operations. Although it's not ideal or where I would have wanted to be, it's nice that I was able to achieve something and it gives me a slight sense of purpose. I do still have to claim benefits, which I have relied upon since I met Mark Simmons at the QEH who helped me to get what I needed for a better quality of life. Had I been able to receive structured education I believe I would have had a fairly lucrative career.

38. In October 2006 I met a woman at a bereavement weekend through the MacFarlane Trust. It was love at first sight. Things moved very fast and Michelle and I got married in May 2007. It all just felt right.

39. I had a great financial advisor called Susan Daniels who helped me to get on the property ladder via shared ownership. When my wife and I moved we were able to apply to Nationwide for an extension to our mortgage, and this was only given to us as I had a letter stating that I had guaranteed payments for life.

40. I have looked into life insurance but no one would touch me with a barge pole. I used to be unable to get travel insurance but now that I am able to get the insurance, it is just extremely expensive.

41. Michelle and I decided that we would try for children **GRO-C** **GRO-C** It was very stressful for us, especially for my wife, but we eventually had a little girl who was born in 2010.

42. We then started to receive advice from a study in Switzerland which said you can't pass on HIV when you are virally suppressed. We therefore tried for another child and we had a little boy in 2011 **GRO-C**

43. **GRO-C**

44. In 2013 I was treated with Telaprevir, Interferon and Ribavirin in an attempt to cure the Hepatitis C virus. I think they were pushing me to have the treatment as my Fibroscan results were getting worse. I considered waiting for new treatments to become available but they didn't know when these would be ready. They told me that I would feel 'fluey' after my Interferon injections, but that was all they told me. In reality, taking those drugs caused me to feel the worst I have ever felt in my entire life.

45. During the first few months of treatment, there were several weeks when I couldn't even get out of bed. It caused severe anxiety and panic attacks. There was no reason to feel like that, it was just chemically induced. I was taking Valium to try and combat my anxiety and I am still on anti-depressants. My skin was terrible. The treatment made it super sensitive. I also had to take a certain amount of fat with the Telaprevir so it was like drinking a cup of oil every time I had to take the medication. That was supposed to prevent diarrhoea (which was a known side effect); but it didn't work.

46. I didn't feel like I could be left on my own with the kids when I was undergoing treatment. It must have been so difficult for my wife to deal with everything for that year, as we had two young children and I was in a very bad state.

47. I was told that the Telaprevir would give me a much higher chance of clearing the virus as I was genotype 1A; however they said there was still a good chance I may not clear it. Normally with the Telaprevir it would only be a six month treatment but they made mine a one year course due to the fact I was co-infected with HIV. I subsequently found out they were putting some people on anti-depressants before the treatment started.

48. I don't remember receiving any real targeted nastiness as a result of my infections. There was almost the reverse where people who knew about my infections were overly nice to me. Since I have started telling people and have been campaigning I have received no negative responses.

49. I continue to suffer from osteoporosis (as a result of my HIV medication), avascular necrosis of the femoral heads, reduced left side function after my stroke, fatigue, dizziness and liver fibrosis.

50. I currently receive treatment from the Royal Orthopaedic Hospital, Worcester Royal for my HIV treatment and the QEH for liver monitoring, endocrinology, dental and my haemophilia; just attending appointments can be a full time job.

51. I know a lot of people who were infected at an older age and have had their world ripped apart. For me, as I have always suffered from medical issues it is simply all I've ever known. I had always thought I just had low motivation until someone told me that I could be depressed. When I started going to Worcester Hospital they gave me sheets to fill out and they said that I was borderline depressed, so it is possible that I have always suffered from depression.

Section 6. Treatment/care/support

52. I joined the Partnership Group in or around 1999 after a weekend event for younger infected people which was organised by the Haemophilia Society. This was the first time I had met people going through the same thing as me. I left feeling like I wanted to be more involved. I went down to meetings in London every few months to discuss how we felt they could help people better.

53. We had a great social worker at the QEH called Mark Simmons who was always there to listen; however counselling was never offered to me or my family.

Section 7. Financial Assistance

54. I was a part of the 1991 HIV litigation. As I was a child, it was my parents who were made to sign the waiver. They were bullied into signing it as they were told if they didn't sign it then nobody would receive anything. As I was a minor

with no dependants, I received the lowest payment possible. Furthermore, as I only had a few years to live, the money just fizzled away as there was no reason to think long-term or plan for the future.

55. I didn't know the MacFarlane Trust existed until my Mum told me that I could apply for grants. They were paying a regular monthly payment to my Mum but it wasn't much at all. I later received a grant to study at the Open University. I received grants for a motability car every three years for about nine years. I believe I also had a moving grant from the MacFarlane Trust when I moved house.

56. Towards the end it was very difficult to get anything from the MacFarlane Trust. They would ask for a detailed breakdown of expenditure and it would then be refused in any event. I therefore didn't have the energy to apply for grants, nor have I with EIBSS as I believe it will yield the same results.

57. I received the Stage One payment from the Skipton Fund.

58. Under EIBSS I am classed as co-infected having passed the SCM. I haven't had any grants but I get monthly payments and the maximum top-up payments. These payments allow me to sustain a reasonable standard of living but there is no security because the Government will not confirm that the payments will continue to the end of my life.

59. As our money is only guaranteed until our next spending review, it makes it very hard to plan for the future as I don't know how long I will continue receiving this money.

Section 8. Other Issues

60. I remember seeing my records wheeled through the Children's Hospital and I know there were a lot of them. There is a reference in my medical records to seven volumes of records, but when I received my records I do not believe they were all there. I want to know why I have not been provided with my full

medical records and why so many other haemophiliacs have faced the same problem.

61. I have spent a lot of time helping to create Tainted Blood and providing support for our community. Due to the research and time I have put into infected blood, I would be able to provide the Inquiry with information about the matters raised in the Terms of Reference. However, this information is not covered in the remit of this statement.

62. Pursuant to paragraph 2.9 of the Notice of Determination in the Award made to my Solicitors preparation of this statement does not cover investigative work. I would like to give evidence on the matters set out at Paragraph 61 above and I am unable to do so in this statement.

Anonymity

63. I do not wish to be anonymous.

64. I would like to give oral evidence to the Inquiry.

Statement of Truth

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

Signed... GRO-C ....

Dated 27th February 2019