Witness Name: Ian Jones
Statement No: WITN1316001
Exhibits: WITN1316002
Dated: November 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF IAN JONES

I, Ian Jones will say as follows:-

Section 1. Introduction

1. My name is Ian Jones. My date of birth is GRO-C 1954 and I live at GRO-C GRO-C I have been married twice and have two children who are now grown up and have families of their own. I am retired.

2. 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

3. I have severe Haemophilia A and I was the only person in my family to be diagnosed.

4. I was under the care of Dr GRO-D at Manchester Royal Infirmary (MRI) and prior to this I attended Blackburn Royal Infirmary Hospital (BH).

5. In or about 1981 I believe I first received Factor VIII (FVIII) at the MRI. I also received FVIII in BH in or around 1986. Further information about the treatment I received is exhibited at **WITN1316002** (National Haemophilia Database). Prior to receiving FVIII, I was given Cryoprecipitate.

6. In or about 1981 when FVIII became available to me we were able to administer the drug ourselves and it was life changing. It bought normality to my life, for example, I was able to travel anywhere I wanted and if I had a bleed I was able to administer FVIII myself. My visits to the hospital also reduced and my children were able to live a normal life by attending school regularly without being rushed to the hospital in the middle of the night. I was trained how to administer FVIII by the doctors and nurses at the MRI.

7. I would administer FVIII when I had a bleed until August 2015 when I then started taking prophylactic treatment every three days. I would only administer FVIII when I had a bleed.

8. During training I was on the equivalent of several different batches. I did question at the time why I was given many different batches, but the nurse at the MRI told me that they were using them up. I did not question this further. I was only given a single product after I finished the training.

9. No one told me beforehand about the risks of being exposed to infections from the infected blood products. I did think at the back of my mind that there was a slight risk of being infected with an infections as you are injecting foreign bodies into your own body. However, I did not know to what extent the risks where and I did not know the infections could be as serious as HIV or Hepatitis C (Hep C). I do recall reading a haemophilia leaflet, which I received from the haemophilia society that stated FVIII was safe to use.

10. I believe I was infected with HIV, Hep C and Hepatitis B (Hep B) as a result of being given infected blood products. I note from my medical records that I have been tested for Hep A, B and C and HIV without my knowledge.

11. In or about 1985 I received a letter from Dr GRO-D at the MRI stating I had been infected with HTLV3, which meant nothing to me. This letter is missing from my medical records and unfortunately, I did not keep a copy. The letter just stated that an antidote would be available soon after receiving the letter. I did not receive any further communication about this and because no one followed it up from the hospital, I did not think it was serious and did not contact my doctor.

12. Approximately six months later after receiving the above letter, I went for a regular check-up, in relation to the haemophilia. I saw Dr GRO-D at the hospital and this was when he told me that I had HIV. He accused us both of being a selfish parents, which I now know is associated with the fact that I could have passed the infection onto others. I was shocked to be told that I was HIV positive and only to be told when I had a regular check-up. Dr GRO-D told me I needed to have safe sex and that I need to wear a condom. As my results tested positive for HIV, my wife GRO-C

GRO-C

13. I was also told at the appointment that I had between 6 months to 10 years to live. That also shocked me. However, it did not have a major impact on me at the time because my parents were told by the doctors that I would not make it past my teenage life because of my haemophilia. However, it was still a shock to hear that I only had between 6 months to 10 years to live because of this infection.

14. I believe I was not provided with adequate information about HIV, Hep C and B. I was just told that Hep A was like a jaundice type of infection and Hep B was a little bit more serious but not life threatening. I cannot recall receiving information about HIV, other than what Dr GRO-D told me.

15. In or about 1993, I was tested Hep C positive. I had no knowledge that a blood test was done for Hep C. I recall being told about Hep C, but I am not

sure how I received this information. I cannot recall if I received a letter from the doctors to confirm that I was Hep C positive and how I could manage the infection.

16. I believe the information about HIV should have been provided to me earlier. As previously stated I only found out after 6 months of being tested positive for HIV. Between this time I could have infected my wife and it could have been too late.

17. I believe the information about Hep C should have been provided to me earlier. Initially I was not worried about Hep C because of the way HIV had been portrayed and I thought this was a bigger concern. I then discovered how dangerous Hep C could be, but I did not get this information from a doctor, I did my own research on the internet.

18. I was not happy with the way the results were given to me in relation to HIV. The communication was very poor, and I would have preferred a face to face meeting, with more information about the effects of my diagnoses.

19. I do not have any views about how the results for Hep C were communicated to me because it was just very run of the mill.

20. I was not given any information about others being infected with HIV until six months later (as previously stated) when the Dr **GRO-D** told me to use condoms but by then I felt that it was too late as there was a possibility that I could have infected my wife.

21. I started taking precautions for the HIV, but I was never told how dangerous Hep C was and that I could also infect my wife. It was only when the internet came about that I realised how dangerous it was.

Section 3. Other Infections

22. I strongly believe I was infected with other infections as a result of infected blood products. I received a letter in or about 2004 stating that I had been exposed to vCJD. They did not know if I defiantly had vCJD but somebody who donated blood had died from vCJD, so I therefore consider it was very possible that I was infected with other infections. Dr Hay (who took over from Dr GRO-D did not tell me anything about the vCJD, so I did my own research. The internet was my saviour because I was able to find out answers that the doctors did not tell me.

23. At the back of my mind, I do wonder if I was infected with anything else which the doctors knew but did not tell me.

Section 4. Consent

24. I believe I was tested without my knowledge, consent and without any adequate information. I was told by the doctors that I have HIV, but I was never told that I was being tested for it.

25. I had a feeling that the doctors were testing me for something when I went for my haemophilia blood tests, but they never sat me down and told me exactly what the tests were for.

26. I believe I was tested for the purposes of research, which I do not mind if the tests were to enhance medical knowledge about haemophilia. It would have been nice if I was told that I was going to be tested for research purposes.

Section 5. Impact of the Infection

27. I feel that I have been on a death sentence for the last 33 years. It is bad enough to be told you have between 6 months and 10 years to live but to be told you may have infected someone you love, who is the mother to your children nearly sent me over the edge. Putting my wife at risk was

unforgiveable. I had two kids around four and six years old and they could have been left as orphans because of the stupidity from the hospitals.

28. When I was told I had to have safe sex I realised then that I would not be able to have any more children. I also believe that my ill health and depression played a part in both of my marriages failing.

29. I believe that I have been very lucky as I have not had many physical side effects from the infections. I had a few night sweats at one stage and I had weird spots down one side of my leg which the doctors said was HIV related. The spots cleared up after a couple of weeks. Even though I had very minimal physical side effects it was always at the back on my mind. You never know when symptoms related to HIV and Hep C are going to start. Sometimes I woke up with headaches and wondered if that was the start of my immune system breaking down. These thoughts always played havoc in my mind.

30. The first treatment that was available to me in relation to HIV was AZT. I recall taking twelve tablets a day for approximately ten years. I then stopped the medication as I thought they did just as much harm as good. I only started taking the medication for HIV again when I started to get age related complex and my T4 count went down to 40 and I was told that the damager level was 200.

31. Even though I did not get many physical side effects, I feel that my life has been ruled by tablets. I had to get up at 4 in the morning to take tablets and it took a lot out of me.

32. I suffered from depression as a result of being infected and I was prescribed Fluoxetine. I did not take the medication because I already had enough tablets to take.

33. I had a friend who came to the MRI with me. I used to pick him up and we would go and have treatments together. He was a good character and a

great laugh, but he committed suicide because he could not handle it. The infections have ruined my life. When the main rug has been pulled from under your feet and you know you are going to die you just wonder from which infection, HIV, Hep C or mad cow disease. I now dread letters from MRI.

34. I have had no difficulties accessing treatment for HIV. They were throwing treatments at me like it was confetti. I attended the sexually transmitted disease clinic at the BH to get treatment for HIV and it made me feel dirty. I believed that I should not have been there because it was not my fault I had the infections. I stopped going to the clinic after about 6 months because I felt that it was very disrespectful.

35. In the early to mid-1990s I knew interferon treatment was available, but this was not offered to me. However, I would not have taken it anyway because a lot of people said how awful the treatment was and on top of this it did not have a high success rate. I was not keen about the miracle cure because the first miracle cure got me in a massive mess. I did a lot of my own research before I accepted any type of medication or advice because I had lost all faith in the medical profession.

36. When I finally had the Hep C treatment (I cannot recall the name of the medication) approximately two years ago I was told that the virus was untraceable. I was on the medication for approximately 3 months. I was lucky at the time as I did not suffer from any physical side effects. However, it did affect me mentally because the treatment only had a 90% success rate and it was always playing in my mind that I might be the unlucky 10%. The treatment worked and I cleared Hep C last year. I still have liver scans on a regular basis.

37. The infections have had an impact on my children's upbringing. There were a few occasions when my children were sick I had to move to out. My children had to grow up with a sick father. When I was having Hep C treatment, I did not tell my children because I feared the treatment may not

have worked. I also felt that they had been through enough. I felt that I was limited to travel after I was infected with HIV and Hep C because I could not get travel insurance. I was banned from America at one stage.

38. The stigma associated with HIV and Hep C was devastating. I would deny having HIV and just bottled it up. When it came to light that haemophiliacs had been infected, I just lied and said I was one of the lucky ones that was not infected. At the time my children were starting school and I did not want it to affect them.

39. I have lost a few friends after I told them about my HIV, but I guess they were not true friends. My father also never knew about my situation, but we never talked about it.

40. Even at the haemophilia clinic we would not be open about our infections, as we did not know who would be listening to our conversations. It would just be a wink, or a nudge and we would just know. Now with the tainted blood group people are more open about their situation.

41. I felt that doctors treated me differently after I was infected but I can understand it. On one occasion I took a full sealed box of needles to the hospital and the nurse asked me to put it on a chair and when I looked back, she had gone to put rubber gloves on just so she could to pick up the box. If a doctor or nurse would take my blood, I would tell them to put rubber gloves on.

42. I felt that the information the media portrayed was wrong in relation to the gravestones falling down. The adverts were very degrading.

43. I had left school when I was infected, so the infections did not affect my education. My work was also not affected because a retired prior to being infected.

44. I do believe that the infections have had a massive financial effect on me. I got to a stage when I was in debt and I thought 'to hell with debt' because I

thought I was not going to live very long anyway, but I outlived what the doctors told me. I have now paid off my debt.

45. I was also told to have a healthy eating lifestyle which I found and still find to be very expensive. I do try and live my last few years as best I can whilst making the most of the time I have with my kids.

46. I cannot get a mortgage or life insurance because of the HIV. Therefore, there would be very little left for my wife and kids.

Section 6. Treatment/care/support

47. I have faced difficulties getting medical treatment on many occasions. Approximately 9 years ago, I needed both my cataracts operated on, but I think they had to delay my treatment because of the HIV and Hep C. On a similar occasion I needed a hernia operation about seven years ago and this was also delayed. I think it was because of my infections. The health service infected me but I feel that I am being punished for operations because of the infections and the risk of my infections to medical staff.

48. Counselling and religion were thrown down my throat after my diagnosis with HIV. They said they could turn to god and he would help me, but at that time I thought I would rather rely on the pills. I did turn to the alcohol at some point as I wanted to forget about everything, but this was the worst decision I could have made.

Section 7. Financial Assistance

49. I have been a part of the Macfarlane Trust in or about the late 1980s but I cannot remember how I became a part of it.

50. I received a lump sum payment in the sum of £60,000 from the Macfarlane Trust in the early 1990's and a second payment in the late 1990's. They

said that everybody had to sign a waiver otherwise no one would get the money. I just signed it as I had no financial income and thought I did not have long to live. I learnt after signing the document that there was a hidden agenda that I was unable to bring any future claims.

51. I also received £20,000 as stage 1 payment from the Skipton Fund because I was Hep C. I received a letter from Skipton informing me that I was entitled to above sum of money. I filled in the form and then sent a copy to my doctors. There were no difficulties or obstacles this application.

52. I get monthly payment from EBISS now. I get approximately £1800 a month and I also get a winter fuel allowance in the sum of £500 annually.

53. I applied for a new washing machine in the early 1990's which Macfarlane paid for. They also paid for two holidays and a new step which was put by my front door.

54. The process for applying for the washing machine, holidays and new step was very degrading. You had to provide a lot information. I felt I had to jump through a lot of hoops to get somewhere. About eight years ago if you applied for something they would refer you to social services. Only when social services say no do Macfarlane listen. Now I do not ask for anything because it is too degrading.

55. I believe Macfarlane realised they were spending the finances quicker than they expected and people were living longer than expected so they are now having to tighten their purses. At one point they let me have a video camera, so I could record my children growing up but now there is no way I would be granted this.

Section 8. Other Issues

56. I am a member of the Tainted Blood Group which keeps me up-to-date. The hemophilia society have started coming back on our side, but this annoys

me as prior to this they said FVIII was safe. I would like to go on some campaigns, but they are all in London.

Conclusion

57. I want justice and the people who were responsible to be made accountable.

Anonymity, disclosure and redaction

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

Statement of Truth

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

Signed **GRO-C** ....

Dated 28/11/18