Witness Name: Genevieve Jones
Statement No.: WITN0465001
Exhibits: Nil
Dated: 3/4/19

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GENEVIEVE JONES

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 12 March 2019.

I, Genevieve Jones, will say as follows: -

1. Introduction

1. My name is Genevieve Jones. My date of birth GRO-C 1960 and my address is known to the Inquiry. I am a widowed, mother of two and I work at a supermarket as a catering assistant. I intend to speak about my Hepatitis C (HCV) antibody diagnosis as a direct result of receiving contaminated plasma. In particular, the nature of my diagnosis, how it has affected me, and the impact it has had on my family.

2. As a result of the fact that memories fade over time, I have remembered some parts of my experience by anchoring it to other memorable times in

my life. I am not legally represented and the investigators have explained the anonymity process to me. I have chosen not to seek it as I have a common surname and I do not believe people will know who I am from reading my statement.

2. How Infected

3. I was living with my parents in GRO-C when I discovered I was six months pregnant with my first child in 1979. My daughter was born in Woking Community Hospital and due to the delivery being faster than anticipated consequently I suffered a heavy bleed. I was rushed by ambulance to the Royal Berkshire Hospital.

4. I was given a plasma drip and was in hospital recovering for forty-eight hours.

5. To the best of my knowledge, I do not believe that I was provided with any information prior to being given blood products, nor was I told of the risk of being exposed to an infection.

6. Between the years of 1982 and 1989 I was an avid blood donor. I achieved a blue badge for donating a certain amount of blood. I was notified of the fact that I had contracted HCV through a letter I had received from the Blood Transfusion Service, which operated in England and Wales, in 1989. The letter explained how I could no longer give blood due to the fact that they had found HCV antibodies in the blood that I had donated.

7. The letter, of which the whereabouts is unknown, thanked me for my service over the years but advised me not to give blood in the future and to contact my GP to have tests. I do not recall if I was provided with any informative documentation or a list of symptoms on how to manage or understand my infection.

8. I went to see my GP, with my late husband, and showed him the letter. I am unable to recollect if I was asked a series of questions as to how I had contracted the antibody, nor can I recall if he sent me for blood tests. The GP told my husband to wear protection during intercourse, as I was only told that it could be transmitted sexually, and referred me to the Royal Free Hospital in London.

9. It took six weeks to get an appointment at the Royal Free Hospital. The first appointment was in November 1989 and I saw a male consultant, whose name I cannot recall. He asked me whether I took drugs or shared needles, of which I do neither.

10. I underwent a series of tests that consisted of liver function tests, blood tests, a test that checked for the virus and antibodies and a few others. I am unsure as to whether I was tested for having HIV.

11. I then had a conversation with the consultant, who told me that I need to be monitored every couple of months to check that my liver was working properly. I was given no advice about whether I needed to take any medication and was just told to keep an eye on it every couple of years.

12. A while later I received a letter from my GP requesting that I make an appointment with him. He was sympathetic in telling me that my results taken at Royal Free Hospital were back in and that they is no active virus, however they had found that I am HCV antibody positive as the letter from the Blood Transfusion Service had told me. He marked it on my notes and told me to keep an eye on it.

13. Following this, every six months I went back for tests. The first follow-up appointment was at Royal Free Hospital and then at Prince Philip Hospital, GRO-C.

14. During my second appointment at Prince Philip Hospital, they were considering taking me off of the list to be monitored, however I told them that I wanted to keep being checked.

15. I would like to mention that at no time, at any of the hospitals that I visited for tests and appointments, was I told of the HCV symptoms. I have no recollection as to whether I was told how to manage the illness.

16. I believe that it would have been "nice" to have been provided with information at an earlier stage regarding HCV antibodies, as the infection has had an impact on my mine and my families lives.

17. In regards to being informed of the potential risk of infecting others, I was told only to make sure my husband was protected with condoms during intercourse due to the infection being one that can be sexually transmitted.

18. The test results were not communicated to me and I believe that it would have been nice to be told that my results were ok. I do not want to go to the GP as I feel as though I would be wasting an appointment and his time. I will be seeing the Practice Nurse very soon and hope that I will be able to get some information at that appointment.

3. Other Infections

19. I do not believe I have contracted any other infections as a result of receiving contaminated blood products.

4. Consent

20. I do not recall whether I gave consent for the plasma drip that I received or whether there was a conversation regarding the need for

the blood product. Logic dictates that I most likely gave consent, as I believe the blood I received was in aid of saving my life.

21. In the likely situation that I did consent, I would have consented to safe medical care. I trust medical professionals and accept what they say to be true, however I did not go into hospital to be deliberately infected.

22. I was not told of the risk that I might receive blood contaminated with HCV, Hepatitis B (HBV) or HIV.

23. I do not believe that I was treated or tested without my knowledge.

24. To the best of my knowledge I do not recall being treated or tested for research purposes.

25. I do not believe that I have been treated or tested without full or adequate information.

5. Impact

26. Following my HCV antibody positive diagnosis, it has played on my mind for the last forty years. Initially, I felt unclean and dirty when I found out that HCV is sexually transmitted, although I had only ever had sexual relations with my late husband in the previous thirty years. I was worried about what people would think or assume of me, as the people in the area of which I live are quite small-minded.

27. I felt guilty because my late husband, whom had a rare blood type, used to give blood for new-born babies. This, however, had to come to a stop due to the fact that I am HCV antibody positive. He declared it to the blood authorities, who dictated that he could no longer donate.

28. Alongside this, I was worried that he may have thought that I may have been having an affair with someone. The thought had occurred to me that he may have had an affair with someone and passed it on to me. I do not believe that it is fair, that I had to question the loyalty in my marriage due to contracting the infection in a way that was not my, nor my late husband's doing.

29. I didn't share the fact that I felt unclean, dirty and guilty with my husband because I felt ashamed. Outside of the family however, I have not told anyone, including my work colleagues.

30. When I was told about my infection through the letter I received from the Blood Transfusion Service, I was taken aback. I was upset and had no idea what HCV was or what the implications were of having HCV antibodies.

31. In the appointment that I had with my GP once he had my results from the Royal Free Hospital, I believe the entire conversation went straight over my head. I don't think I understood the nature or the gravity of what he was telling me.

32. The physical affects of having HCV antibodies have not materialised as my body has managed to fight off the virus. However, not long after I moved to Wales with my husband, I felt rather ill with flu-like symptoms. My husband called the GP whom told me that it was just a cold. This may be unrelated but I believe it is worth mentioning.

33. Due to the fact that I don't have the virus, only the antibodies, I have not required medical treatment other than on going monitoring on a six-monthly basis.

34. Upon reflection, I am unsure whether I have received the whole range of tests and whether this should be done. I was never offered it and so I never asked.

35. I have mentioned to my dentist that I have tested HCV antibody positive. This has not affected the way I have been dealt with as a patient and I am treated the same way as I was prior to telling them of my diagnosis.

36. In my private life, my HCV infection is a shared family secret. I have shared the fact that I have the infection only with my closest family. My daughter has become my champion. She asks the questions, research's things for me in order to help me understand the infection. She gives me support. I have been given more information from my daughter than I ever received from any medical professional.

37. I had never worried that I may have passed on the infection to my children. Due to the Inquiry stimulating my interest into my own situation, it has made me call into question the fact that my son may have been infected, as I was pregnant with him whilst infected. I will now have to have a deep and meaningful conversation with my son as this can have ramifications for him, as he is an international traveller.

38. The infection has impacted my social life, as I don't tell people socially that I have the antibodies. Due to there being a stigma around HCV, I felt ashamed and so never thought to speak about it. I believe there would have been awkward conversations and it would have made me feel guilty for my late-husband if people knew that I had the infection.

39. I haven't shared my diagnosis with my friends or work colleagues due to the stigma attached to HCV. If someone shouted out that I have HCV antibodies, I would be mortified. I believe people would assume that I am a drug addict or part of the homosexual community, or that my husband was.

40. In the late 1980's and throughout the 1990's, the media campaigns focused on HIV as opposed to Hepatitis. They were all about sharing

needles or the homosexual community. There was never any coverage or campaigns surrounding HCV however I believe people would assume that I would have got it somehow. I believe that the assumptions within my social circle and the wider community would gave been that I would fall into one of those groups.

41. I wouldn't want my children to have been stigmatised because of me. If people knew, I would have been worried that my children's friends wouldn't be allowed to come for sleepovers as their parents may have been in fear that my house is contaminated, dirty or assume that there would be needles all over the place.

42. I have chosen not to share my diagnosis with work. I assume that they would think that I am dirty and would associate me with drugs and needles. I live in a high drug-using area and I am surrounded by a drug culture that I am not a part of.

43. As a result of being made redundant from my job, of which I have worked at for thirty years, I now have to consider whether I will have to disclose my HCV infection on job applications. If I don't and fall ill because of the infection, it could cause problems. As a result of this, I now feel scared, apprehensive and uncertain of what the future will bring and be wary of the financial implications I may face as a result of potentially not being able to find another job.

44. At a certain age it can be difficult in obtaining a job and I will now have to think long and hard about responses to medical questions. I presume I will still be allowed to work in the catering industry, although I do not know whether this is the case, as I have not received any information from any medical professionals.

45. I have never been reimbursed or compensated for the cost of travel to London from Wales and back again for appointments, or to and from my GP and local hospital.

46. Medical professionals have never told me that I would need to add the fact that I am HCV antibody positive to my travel insurance.

47. For the impact that my HCV antibody diagnosis has had on my family, please read my daughter, Christine Thomas' statement in conjunction with mine.

6. Treatment/Care/Support

48. During my visit to the Royal Free Hospital I was told that screening was only available for HIV patients and that there was no screening accessible for HCV infected patients.

49. It would have been nice to have someone to sit down with to give me some information and counselling, as I was feeling guilty, upset, ashamed and angry. At the time however, I just got on with life, as I had no choice.

50. I have not been offered counselling nor have I had any professional support of any kind. The Inquiry has now made me aware of the work that the British Red Cross (BRC) are doing to help with counselling for people who have been infected and affected by infected blood. I have been provided with a card with the BRC's counselling details and I will consider whether I will access this service.

7. Financial Assistance

51. I have received no help or financial assistance from any of the previously set up trusts and that includes the current regime in Wales[1].

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[1] Wales Infected Blood Support Scheme.

52. My daughter, on my behalf, made enquiries to a Trust, of which I am unsure of the name, but she was told that I did not qualify. She was not told an explanation as to why I am not eligible nor did they share with her what the criteria and conditions were for applying. We accepted this as gospel. We are very trusting people.

53. I have considered the fact that I may have been earning too much to apply, as it may be means tested. However, my circumstances have now changed and so I may consider applying. If I had to go to the Royal Free Hospital in London again, I would struggle to afford it and would therefore have to forego any treatment or appointment offered to me.

54. I am unable to recollect how my daughter and I became aware of the fact that I could apply to a Trust for an ex gratia payment.

8. Other Issues

55. Upon reflection, it raises a concern in my mind now, at this moment in time, that I have not had any liver scans or tests and I do not receive regular updates from medical professionals. I have to assume and accept that everything is fine and that I am ok, as I am never told the outcome of results. It would be good to receive reassurance that everything is ok. I think I may have been complacent by trusting that medical professionals would tell me if something is wrong but I am unsure.

56. I have never been told that I have received contaminated blood products however; I believe that the only explanation for my diagnosis is due to the fact that the plasma that I received in 1979 was contaminated.

57. Something that has been playing on my mind is the fact that I had been giving blood following the plasma I had received in 1979,

between 1982 and 1989. I decided to give blood as I had received it and I believe it saved my life. I wanted to give back and tried to do a public service.

58. The thought that I may have potentially infected other people makes me feel very guilty, as I was trying to do a good thing.

59. Being told that I can no longer give blood made me feel ostracised, ashamed and in all honesty makes me feel like crap. It's as though I am being told that my blood isn't worthy.

60. It is typical of our caring sharing government not to announce the fact that there was a problem with the blood supply in the UK. They brushed it under the carpet in hopes that it would go away.

61. I would like an apology or some form of admission from the NHS and for the government to take some responsibility. I want those responsible to put their hands up and admit liability. I want the truth to come out and ensure that this will never happen again – somebody must have known.

Statement of Truth

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

Signed GRO-C

Dated 3/4/19