Witness Name: Jean Smith
Statement No.: WITN0083001
Dated: 25th April 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JEAN SMITH

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 8 January 2019.

I, Jean Smith, will say as follows: -

Section 1. Introduction

1. My name is Jean Smith. My date of birth is GRO-C/1956 and my address is known to the Inquiry. I am married with a son and work as a part-time teaching assistant for children with learning difficulties in a mainstream school. I intend to speak about my experience of being infected with Hepatitis C ("HCV") from a blood transfusion. In particular, the nature of my illness, how the illness affected me, the treatment I received and the impact it had on my family and I.

Section 2. How Infected

2. In 1990, I suffered an ectopic pregnancy and was rushed to Greenwich Hospital. By the time I had reached the hospital, I had lost a lot of blood

and was given a blood transfusion. A nurse told me the following day, that I had been in a life-threatening situation at that time. When I was given the transfusion, I was apparently not in a condition to give consent as such. However, I can say that had I been asked for consent at the time, I would have undoubtedly said "yes", if it was to save my life and that was what the medical staff said needed to happen. Of course, had I known the origins of the blood I was being given and risks involved to me, that may have been a different matter. To be clear and it may sound obvious but I was not told of the risk of infection, prior to being exposed to the HCV.

3. I found out that I had contracted HCV following a Sexually Transmitted Disease Test (STD) at a Sexual Health Clinic. As a result of suffering from a skin condition around my lower 'private area', that my GP struggled to treat. I took myself to a local clinic to see if they could help me. The sexual health nurse advised me to take an STD test and gave me some Canestan.

4. The sexual health nurse called me approximately two weeks later, and told me that I had HCV and informed me that he would send me a referral letter to see a doctor along with some information leaflets on the infection. I was in utter shock as I had had only one sexual partner in my life, my current partner, Roy.

5. I was under the impression at that time that HCV was a blood disorder and that it could not be treated. I do not believe that I was aware that HCV attacks the liver. I did know at that time however, that HCV could be passed on to others.

Section 4. Consent

6. As I previously stated; when I received the blood transfusion, I was not in a position to consent to the treatment and later learned that I was in a life-threatening situation. I did not however, consent to being given HCV.

Section 5. Impact

7. I was not aware that I had been infected with HCV up until five years ago, 24 years after the blood transfusion that gave it to me. The skin condition that I referred to earlier in this statement was subsequently diagnosed as Lichen Planus. It appeared on my back, then other places including my private area, hence after my GP struggled to help treat it, I went to a Sexual Health Clinic to see if they would know more. I felt as though I had nothing to worry about in regards to the results of the STD test and so I wasn't necessarily awaiting the results.

8. I remember the day that I received them very clearly though. I was in my garden when I received a call from the sexual health nurse from the clinic. He informed me that I had contracted HCV and that I needed to see a doctor at Darent Valley Hospital. Initially I told the nurse that he must have the wrong notes, and that it could not be my results he was referring to. The nurse assured me however, that he was referring to the results from my test. The indignity was compounded by being told over the phone by a sexual health nurse. This had an impact on my confidence and self-esteem. I could not work out how this could have happened to me.

9. Being diagnosed with HCV had a devastating effect on me. I was shocked because I had never been promiscuous, or involved with drugs. I had led what I would call a normal lifestyle. The shock lasted until I saw Dr Melia. I was in fear of the unknown.

10. Once I was diagnosed with HCV I panicked about my son and my partner and whether I had passed it on to them. I was very careful with toothbrushes and cleaning up if I cut myself. I was extremely conscious of my son contracting the virus. GRO-C GRO-C GRO-C I have never told my son that I had HCV as it would be too difficult to explain it to him sufficiently, particularly after all these years. I had my son in 1991; one year after being infected GRO-C

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12. The sexual heath nurse sent me some informative leaflets about HCV and also a referral letter to see a doctor at Darent Valley Hospital. There was a three-week wait between learning that I had HCV to when I had my first appointment with Dr Melia at his liver clinic. He was a very nice, knowledgeable doctor however; he solely ran the Darent Valley Hospital's liver clinic, he was a 'one man band' and as such they seemed to lack the resources and funding that a larger hospital would have. That said the service that he provided was very personalised and I felt that he knew me.

13. Dr Melia asked me a series of questions to determine how I had contracted the virus. He asked me, in this order; whether I had received any dental treatment abroad, whether I had been a prostitute, whether I had been a drug addict and whether I have had any tattoos. The final question that I was asked was whether I had received a blood transfusion.

14. When I was asked the questions as mentioned above regarding how I had contracted HCV, I felt deflated, embarrassed and worried about what the doctor thought of me, when he was asking me those questions. Once both Dr Melia and I realised the infection was due to the transfusion, the doctor told me that I needed to think about suing someone and said no more about it. I think it would have been much better, given the way in which I presented myself, if I had been asked about whether I had ever had a blood transfusion first. This was not in the early days of infected blood, when there was ignorance of its existence. The problem was well known by this stage.

15. Dr Melia informed me that due to him having such a small department, he didn't have access to the treatments I needed and that I would have to be patient.

16. I was told during one of the early appointments with Dr Melia that I had 'Geno type 1' of the Hepatitis virus and that it was the hardest type to treat. This and the fact that I was being told that I would have to wait, had a huge impact on me at that time. Dr Melia also told me that he had another similarly infected patient, who had had a hysterectomy at Greenwich Hospital.

17. Dr Melia explained at one of our appointments that I needed triple therapy, which was a course of three different drugs, to be taken together over twelve weeks. He told me that he had access to the Interferon and Ribavirin drugs, but not the third, the name of which I cannot recall. Dr Melia told me that it was not worth trying the two drugs he did have access to without the third.

18. In the year that followed, whilst awaiting treatment, I had many blood tests and liver scans. My blood tests, in that year, showed my viral load to be in the millions. The liver scans only presented a fatty liver and no cirrhosis at that time. I was never sent for a biopsy, but I was sent for a fibro scan on two occasions. One whilst I was under Dr Melia's care and another later on whilst being treated at Guy's Hospital's dental department. I found these scans to be very painful due to the fact that they had to push the probes quite deep into my stomach.

19. I waited a year before receiving the triple therapy. In the year of waiting for the treatment, I noticed that I was feeling increasingly tired and lethargic. When Dr Melia told me that he had access to the triple therapy treatment, he also said that I would have to go on a 24-week course as opposed to a 12-week course. This was due to the seriousness of my Lichen Planus condition. It was my dentist at Guy's Hospital, who informed me that there

had been studies in Europe linking Lichen Planus to Hepatitis. I was told that I was very lucky to receive this treatment as others who lived only five miles away would not have received it as quickly as I had.

20. I would take the Ribavirin tablets every morning and evening, the third drug I took three times daily and had the Interferon injections once a week on a Friday. It was my partner who administered the Interferon injections. I decided that a Friday evening was the best time to take it, as I was then able to function throughout the week whilst working part time, allowing me to recover over the weekend from the side effects. Thankfully my partner was retired at this time and was able to take on the housework and shopping. I was absolutely exhausted and was more or less in bed for entire weekends after the Interferon jabs. Usually, when I have a cold or the flu, I am still able to carry out everyday household duties. Whilst I was on this treatment however, I was unable to function well at all in the days that followed the injection. I dreaded Friday evenings because of it. I suffered the side effects of the Interferon very soon after it was administered.

21. The Ribavirin tablets made my haemoglobin levels reduce, so much so that I fainted once whilst out with my friends in Dartford town. It generally made me light-headed, particularly when the weather was hot.

22. I mentioned the light headedness to Dr Melia. He asked me whether I had been experiencing any mental side effects of the Interferon treatment. He told me that Interferon had a history of turning people psychotic, violent and/or depressed. He said that he had taken another patient off the Interferon treatment due to the side effects making her feel suicidal. I told him that whilst lying in bed sometimes when overcoming the effects of the Interferon, I would get a bit down, overthinking things. Dr Melia admitted that at one point my Haemoglobin levels had reduced to a dangerously low level and that it was only that my mental health was stable that he kept me on the treatment.

23. Those 24 weeks of treatment were awful. I had to cut my hours at work and go to a two-day week rather than a three-day week, as the side effects were too much of a struggle to cope with whilst working the hours that I had been doing. I was able to work up until the last month of being on the triple therapy, which was when I had to take time off due to feeling so extremely exhausted. The side effects of the treatment had really taken its toll on me.

24. I had blood tests whilst on the treatment and it was reassuring as well as a relief to see that the viral load was going down significantly and at one stage, it hit nine. I had tests at 4 weeks, 12 weeks and 24 weeks to check the success of the treatment.

25. It was roughly three months following the end of my treatment that Dr Melia, referring to a letter that I did not receive, told me that I had relapsed. It was a terrible blow and I felt dreadful. At the time, I wished I had received the letter rather than having to hear it in Dr Melia's office. I had been optimistic, due to having a 24-week course as opposed to a 12-week course. My viral load had been going down the whole time, I believed I would have been in the clear. I was devastated and went through all sorts of emotions. It had been so tough but I had placed all my hope on that treatment working. I believed it was at the cutting edge of what was available and I worried at that time whether there would be another type of treatment that I could try. I remember walking out the outpatients department at Darent Valley Hospital and having to sit down as the news made me feel as though I was going to pass out.

26. Furthermore, Dr Melia told me that my liver scan had shown early signs of cirrhosis. He said that he would try to get me seen by one of his colleagues at Kings College Hospital ("KCH"), Dr Kosh Agarwal, but that there were no guarantees. I was told that the treatment I needed, which Dr Melia could not get access to, would cost the NHS £60,000. I felt disappointed. Not only had I relapsed, but I was also worried Dr Agarwal would not be able to see me and/or I would not be allowed this treatment.

27. Fortunately, I did not have long to wait before I received a letter stating that I had an appointment with Dr Agarwal at KCH. I did not know what to expect at KCH but when I arrived I immediately knew I didn't like it. It had a horrible smell and it was my husband that convinced me following my first appointment, that I would need to go back, as I really did not want to. It was very different to what I was used to at Dr Melia's practice in Darent Valley.

28. It was noticeable at KCH that liver conditions and hepatitis were predominantly found in drug addicts, alcoholics and people with 'questionable' lifestyles. The waiting room was much bigger than what I had been used to at Darent Valley. I felt as though I had been lumped in with these people, whose conditions were self-inflicted. I felt that I should have had priority, as I had been 'given' HCV.

29. I only had appointments with Dr Agarwal personally, on two or three occasions. There was a much larger team of medical professionals at KCH that it became difficult to build a relationship with just one doctor, in the way I had done with Dr Melia. It made the appointments feel impersonal and also frustrating when it seemed that I had to explain my medical situation to each of them, every time I went.

30. At the first appointment with Dr Agarwal, I was not offered treatment as he told me that he did not have access to it. He informed me that treatments were new and that there were trials but also that I did not fall into the criteria that the manufacturers wanted. I was told that it was the drug companies that funded the trials and so it was they that decided the criteria.

31. I went for appointments at KCH every three months and had a liver scan each time. After the second scan, I was told that my liver cirrhosis had deteriorated further but had not yet reached the point of no return i.e. it

may still recover, if treated correctly. At this point, I felt hopeless due to the cirrhosis getting worse and the fact that I didn't have access to the treatment I needed.

32. I asked Dr Agarwal that if I became a private patient rather than waiting for the NHS, using money received from the Skipton Fund, would I get the treatment any faster. He told me that it would make no difference as to the speed in which I would receive the treatment.

33. After being told I couldn't take part in the trial, Dr Agarwal told me that I might have to wait for quite a while for treatment. It was roughly a year later that I was offered a new treatment. In the mean time I had been going for regular liver scans and blood tests and my viral loading had continued to rise. My viral loadings went up to the thousands, but never up to the millions as it had done prior to the triple therapy treatment.

34. Dr Agarwal eventually told me that he had access to the most up to date treatment available and that the good thing about it was that it didn't involve me taking Interferon. I was told I would need to take Ribavirin and another drug, the name of which I cannot recall. I was told that Interferon had been phased out, as the combination of the Ribavirin with this other drug was so good.

35. I took the new treatment for three months. I didn't have to take any time off of work and I wasn't bed-ridden at any point whilst taking it. This proved to me that the Interferon was the worst part of the first treatment that I received.

36. My viral load went all the way back down to zero and I was told that as long as it stayed at zero I would be clear of HCV. Initially I was told it needed to be at zero for five years, then three and eventually one for me to have cleared the virus.

37. I had liver scans during the treatment and at the end. I was informed after my viral loading had gone down to zero but that my liver was showing significant liver cirrhosis. Dr Agarwal told me that drinking lots of coffee could help with the scarring of the liver and so I drank a lot of coffee around that time.

38. Following my successful treatment, I asked Dr Agarwal if I could return to being a patient of Dr Melia's at Darent Valley Hospital. Dr Agarwal sent a letter to Dr Melia and he accepted me back. I now see Dr Melia every six months for check-ups, which I have been doing for the last two years. I was informed in September 2018 that I would now remain clear of HCV.

39. Since being on the first treatment, which included the Interferon drug, until present day, I have suffered with 'brain fog'. This happens on numerous occasions, for instance, I tend to forget the names of the kids that I work with.

40. My husband has been amazing, the entirety of the time that I have been ill. He carried out all the household duties, including the shopping on a Saturday, whilst I was in bed suffering from side effects and tiredness.

41. It has been tough on him though, as he used to go out occasionally with his friends. When he stopped going, because he was looking after me, he would just make something up to tell his friends.

42. There is most definitely a stigma surrounding HCV, that is linked to a certain type of lifestyle; promiscuity, drug taking etc. I feel as though there are other conditions or diseases that people are sympathetic to but not Hepatitis. This meant that I could not really tell people, that didn't need to know.

43. Having HCV has impacted our ability to go away as a family or on long days out which we used to do a lot. We also used to go to our local workingman's club or to the theatre but I struggle to commit to social

events now due to tiredness. I am usually in bed before 8pm every evening, as I feel tired most days.

44. In my view it seems that contracting HCV has caused me to have Lichen Planus, which is on going, irritable and consistent with liver problems. I was referred to the dermatology and ear, nose and throat departments in Guys Hospital due to my skin condition worsening. I now have the condition in my tear ducts and as a result they are entirely blocked up. In order to resolve this issue, I would need to undergo an operation.

45. My dentist referred me to the dental department in Guys Hospital, as she was concerned about the inflammation of my gums and so I now have special creams, ointments and mouthwashes that I have to use.

46. Other than being given infected blood, I have been mostly content with the treatment I have received from the NHS, particularly the personalised relationship with Dr Melia who was running a very small practice.

Section 6. Treatment/Care/Support

47. I struggled to get the treatment I needed due to lack of access to the drugs I needed.

48. The sexual health nurse was also my nurse whilst I was a patient of Dr Melia's. He was a trained counsellor and so was great support for me.

49. Soon after being told of my HCV diagnosis, I contacted the Hepatitis C Trust. They have been a God-send and I have found them to be so helpful. They have a helpline and a newsletter and I could have rung them asking any question and if they didn't know the answer, they would find it out and get back to me.

50. The Hepatitis C Trust offered me a £900 grant for counselling. They allowed me to find my own counsellor, which I did and visited even after the grant ran out. I found this so helpful.

Section 7. Financial Assistance

51. Aside from assistance from the Hepatitis C Trust for counselling, they put me in touch with the Skipton Fund. They contacted my GP and Dr Melia for medical records and discharge papers. It was a very straightforward process and I heard back within weeks. I received a stage one payment of £20,000 with a pension of £10,000 in monthly instalments. Once I had been diagnosed with cirrhosis I received the second stage payment of £50,000 plus a pension of £18,000 in monthly instalments. I also receive a cold weather allowance payment of £500 around Christmas time. I have put most of the money away for my son who will need it one day.

52. Travelling has become more expensive due to my travel insurance rising by 70% compared with Roy's, due to my cirrhosis. My family and I usually have coach holidays in the UK, which you still need travel insurance for. If I ever go abroad I don't believe I will be able to get insurance.

Statement of Truth

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

Signed GRO-C

Dated 25th April 2019