VRDay.

Witness Name: Valerie Rose Day
Statement No.: WITN0403001
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INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF VALERIE ROSE DAY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 10 January 2019.

I, Valerie Rose Day, will say as follows: -

Section 1. Introduction

1. My name is Valerie Rose Day. My date of birth is GRO-C 1949 and my address is known to the Inquiry. I am a retired veterinary nurse, I am single and I live alone with five schnauzers who are like children to me.

2. I intend to speak about my infection with Hepatitis C following a blood transfusion during a spinal fusion operation in 1984. In particular, the nature of my illness, how the illness affected me, the treatment I received and the impact it had on me and my life.

Section 2. How Infected

3. On 16 January 1984 I had a blood transfusion, it was contaminated with Hepatitis C. I was given two units of blood at Hemel Hempstead Hospital during spinal fusion surgery to stop nerve damage from a slipped disk.

4. In 1984 I had been suffering with severe pain in my back for some time and was eventually diagnosed with a slipped disc by Mr David Hirschowitz FRCS at Hemel Hempstead Hospital. Mr Hirschowitz decided to perform a laminectomy to alleviate the pressure on my nerves, unfortunately the first laminectomy failed and a second slipped disc was found the next vertebra up. So, he performed a second laminectomy operation on that disc. But unfortunately, these two operations were unsuccessful and did not alleviate the pain.

5. Mr Hirschowitz decided another laminectomy would be insufficient so he needed to do a much bigger operation, spinal fusion to fuse the vertebrae together using bone from my hip. Dr Bryant, a nerve pain specialist found that the nerve damage, after four years of pressure from the slipped discs was so severe there was no other option. Spinal fusion is a much bigger operation with more risks. I only had one transfusion during this surgery, I had never had one before. The doctors at Hemel Hempstead Hospital transfused two units of blood.

6. I have never used drugs and I do not have any tattoos. I am not a drinker and I have never even smoked. I wasn't around any drugs as a youngster, of course they existed, but I had quite strict parents who always kept an eye on me.

7. I wasn't told of any risks of transfusion before the surgery, only the anaesthetic risks. They never even mentioned the blood transfusion, I think the surgery was so major that it was just a given that I would have to receive blood. I don't think the doctors knew of the risk of infection from the blood so how could they have warned me?

8. I went to see a doctor in 2007 because I was suffering a lot of joint pain, they diagnosed me with osteoarthritis. Unfortunately, I felt this was

incorrect, and following a google search, I decided my symptoms were more similar to Rheumatoid Arthritis (RA). I informed my doctor of this and fought to be referred to a Rheumatologist.

9. Eventually, I was referred to Dr Bhalarah, a consultant Rheumatologist at Hemel Hempstead Hospital. He was really good. He diagnosed me with RA and put me on drugs for it. I was prescribed self-administered Methotrexate injections at home for three years. However, as soon as I started the injections my liver function tests 'went mad'. I was having three monthly liver checks routinely as part of the treatment for RA and it was one of these that flagged the problem.

10. The liver tests came back and Dr Bhalarah said he was a bit suspicious about the way the liver function had suddenly gone up. He asked me at the time whether I had ever had a blood transfusion before 1991. I said that I had and he told me it was most likely from that. He sent me for a hepatitis screening which came back positive so he referred me to Mr Alistair King at the Royal Free Hospital to see what they could do for me.

11. When Dr Bhalarah told me, I had Hepatitis C I didn't understand where I could have got it from. I have always lived a very clean life but I was a veterinary nurse so I thought, could I have caught it from the animals? That seems silly now but I knew so little about it that anything seemed possible.

12. Nothing was explained to me about my diagnosis, how to manage hepatitis or what might happen next. The lack of information made me very unsure and uncomfortable. I was worried sick. It was 5 months until I got the referral. In all that time I googled as much information as I could but I had no information or leaflets provided to me by the hospital.

13. When I eventually got to see Mr King, it was a relief. I had been suffering with flu-like

symptoms, headaches, nausea and joint pain for so long I had started to feel like I was just making it all up. It was only when I spoke to Mr King and he told me that it's all part of Hepatitis C that I felt validated and realised it wasn't all in my head.

14. At the appointment Mr King said I had to be tested for AIDS and that there was a possibility I was infected with AIDS as well as Hepatitis C. I then had to wait another month for the results of the AIDS test. All the waiting was very stressful indeed. The AIDS test did come back negative though, so that was a relief.

15. Later on, once I was receiving treatment, Teresa Moore, the Hepatitis C specialist nurse at the Royal Free, told me my infection had been caused by contaminated blood. She said the blood had been taken from United States prisoners who had been paid to give their blood, most of them were drug addicts.

Section 3. Other Infections

16. As far as I know, I did not contract any other infections from the contaminated blood transfusion. I think the doctors tested me and ruled out Hepatitis B.

Section 4. Consent

17. I wasn't told of any dangers in relation to the transfusion. It wasn't even mentioned that I would need one when I went in for the spinal fusion. I think it was such a major surgery it was just considered a given that I would have to have a transfusion. Aside from this, I believe I consented to everything.

18. I do not believe I was treated or tested without my knowledge. I am quite hot on it all, I make sure I get the third degree on everything.

Section 5. Impact

19. I suffered a lot of joint pain, headaches, fatigue and flu-like symptoms. I haven't been the same

person since catching Hepatitis C. I'd get up in the morning and wonder why I felt so awful then I'd fall asleep in the afternoon from exhaustion. I used to blame the symptoms I was suffering on all sorts of things because I didn't know why it was happening. I was looking after my mum, so I used to put the fatigue down to being overworked.

20. My mum had a stroke in 1965 when she was only 42, following a hysterectomy. My dad cared for up until his death in 1982, when I became her main carer. This was before I had been diagnosed with Hepatitis C and, as I am sure you can imagine, she needed a lot of care. So this was an especially big strain as I was working full time as well as being her main carer and suffering with the hepatitis.

21. At an appointment with Mr King, he told me about a new drug that had just been released from testing. He said he would like me to start a course of this new drug in July 2007. In the end I had to wait seven months, until January 2008, because it was so expensive (£30,000 per year) and needed funding approval. I had to fight to get the treatment. I made the nurse's life hell trying to get it.

22. I was put on Boceprevir and Ribavirin for six months. The Boceprevir was self-administered at home by injection and the Ribavirin was tablets. At the same time, I was still on the Methotrexate injections to combat the RA, which the doctors told me had been caused by the hepatitis.

23. I took Methotrexate for three years. All together it was quite a load on the old body.

24. The course of treatment to combat my hepatitis was six months of hell. The nurse was fantastic though and told me to stick with it because the markers were going down. The nurse delivered the Boceprevir to the two weekly consultations I had with her at the outpatient's department at The Royal Free and then at Hemel Hospital. I was injecting it myself at home weekly and

taking the tablets too. I felt stressed that it was two weekly appointments as I was never sure I would be able to get to the hospital because I was feeling so ill at the time. Potentially not being able to collect my drugs, living alone and having no back up to get the drugs another way if I needed to was very stressful. She was always at the end of the phone but she came to Hemel Hospital by train and a taxi from the station, so I could not ask her to do a home visit.

25. The injections didn't instantly make the side effects worse. After about a month all the side effects kicked in and it was just terrible all the time. I had so many side effects; I lost hair, had headaches, breathlessness, leg swelling, fatigue and nausea. Then I was also taking all these drugs to try to stop the side effects; there were three drugs just to try to stop the nausea. I'd walk from the outpatient's department in the hospital to the car and they would have to get a wheelchair for me because I was so breathless I couldn't make it the whole way.

26. I also kept getting this cellulitis in my legs. I think that was due to the Hepatitis as well. It was so painful and you need all these antibiotics to clear it, so I was taking those as well.

27. The course of Boceprevir and Ribavirin did work and the doctors have cleared me of hepatitis as much as they can. I still have to be monitored and live with the worry that it might come back.

28. I feel I am stuck in a catch-22 situation as I have been told there is a possible chance the RA drugs can cause the Hepatitis C to become active again but I have to keep taking the RA drugs to help mobility and pain relief. The latest drug I have been given is Humira which is administered by two weekly injections at home. But, before I could begin taking this I had to be tested for Tuberculosis (TB) and again, funding had to be approved on the basis that my joint pain was bad enough for me to qualify for it. Unfortunately, I am no longer on the Humira as I was referred to Dr Julius Cairn, a respiratory consultant at Hemel Hempstead and Watford Hospital, due to problems with my lungs and

breathlessness.

29. I am still having my lung problems investigated but they think it was caused by the Humira. I couldn't even walk to the kitchen when it was at its worst. I am now on Leflunomide, an autoimmune drug, for the RA. I wonder if I have a weakness in my lungs caused by the Hepatitis C treatment. I will be asking Dr Cairn about it.

30. Honestly, since before it was diagnosed, I haven't been the same person. I'm only 70 years old but I feel like I'm 90. I loved gardening, but I can't do that now. I used to have a beautiful garden but now I just find it frustrating. I can't even walk around a garden centre anymore. Being so ill makes you feel like you're beholden to people. I have to have a gardener and a cleaner now but I used to do everything for myself. I also have to be very careful about catching flu, colds and other minor infections because the autoimmune drugs I am prescribed for the RA effect your immune system badly. When my friends catch a cold or anything else they cannot visit me as my immunity is so low.

31. I had a busy social life before the hepatitis. I used to work with a dog rescue to evaluate people who were rehoming Schnauzers. I was meeting new people all the time. I also bred Schnauzers and took them to dog shows. I had to give up the dog showing when I became ill and that had been a big part of my life.

32. I met so many people with the dogs and I really miss that. I was a good Kennel Club listed and inspected breeder of Miniature Schnauzers. I took a holistic approach to it as I felt it was important that people felt they could come and ask questions after they had taken a dog home, so I made a lot of new friends. But I've lost all of that. I've not had children, so the dogs have always been like my children and I've lost nearly all of that.

33. Mentally the impact on me has been so bad I almost cannot say enough to express how bad it is. From the moment I was diagnosed I felt sort of dirty, like it wasn't just the blood I was given

but me, that was contaminated and contagious. I am over fastidious about cleaning and I was terrified of passing it on to others. I've just had a new godson and I was so worried about passing it on to him that I couldn't even hold him.

34. Even now after a successful course of treatment I tell everyone that comes into contact with me about the risk posed by my blood. I really watch medical professionals when they're around me to make sure they're not taking unnecessary risks themselves. I've had four more separate operations on my hands and shoulders since my diagnosis and I make sure all the medics, doctors and nurses, wear gloves and I tell everyone to make sure they're aware.

35. It's quite scary when you don't understand why you've got hepatitis. I didn't find out that the blood transfusion, all those years ago was the cause until I was being treated. It almost would have been easier if there were some cause I could point to from the start but I have lived such a clean life it seemed inexplicable and unfair.

36. I had suffered flu-like symptoms for so long, in a way it was a relief to hear that it was Hepatitis C. I started to doubt myself and thought I was just a hypochondriac. I felt that some people amongst my family and friends lacked a bit of compassion.

37. You just don't know what you're living with until you do a lot of research. Unfortunately, on the Hepatitis C website I'd find everyone's horror stories and that was scary. It was really worrying so I had to cut off at a certain point to preserve my own sanity though I was trying to find out as much as I could.

38. I have never had any counselling. I was prescribed anti-depressants in 2007 by Dr GRO-D, the orthopaedic consultant at the Hemel Hempstead Hospital but there was never any follow up about whether I had taken them, which I hadn't. I used to burst into tears during consultations and the doctor said I might have depression. I was never offered any talking therapies

39. When Dr GRO-D prescribed the anti-depressants, he didn't tell me what they were. He had diagnosed my joint pain as gout and prescribed me some tablets, so at first, I assumed they were for gout but when I looked them up they were for depression.

40. Although I have been depressed, I've not taken anti-depressants because I don't like them and you can get hooked on them. The depression may have been linked to my mother's death. Although I feel bad saying it, I spent 42 years looking after her so it was a relief at first when she died but two years later it all crashed down on me.

41. I struggled with the stigma following my diagnosis, I felt some of my family and friends lacked a bit of compassion and there was a lack of understanding from the people next door. I have been very open about it from the beginning.

42. At first, before I could tell them more about it, people would take a step back when I told them, as if they could catch it just from being near me. I have been thoroughly open, some people would be ashamed but I'm kind of an open book anyway and I was so appalled by it all, I wanted people to know.

43. Having hepatitis hasn't had any educational impact on me, I don't think. I used to go to night school. I was a needle work and cookery teacher and I gave that up when mum got ill. I also used to lecture the vet nurses. I lectured cake decorating and cookery at night school while I was nursing. Since it's been diagnosed I had to give it all up. It's had an awful impact. I did look at studying with the Open University but I don't think it affected my education at all.

44. I had to give up working as a teacher to look after my mum, so I became a vet nurse for a while but when I became so ill I went part-time as a school secretary until I couldn't manage that anymore either. Not knowing what was

wrong, I went and worked part time Friday, Saturday, Sunday and bank holidays for the meals-on-wheels service for the elderly and my cousin came in and looked after my mum while I was out. But then I couldn't lift the meals anymore, I had to have two shoulder operations and I gave up work. It was then that I applied for incapacity benefit.

45. I was about 62 years old when I gave up work completely. I had no pension. I didn't get the government pension until I was 65 years old. Between the ages of 62 and 65 I was living on disability benefit and relying heavily on my family. It was a really big impact when I had to give up the lecturing. I was used to funding my own lifestyle then suddenly I couldn't anymore.

Section 6. Treatment/Care/Support

46. My care has been positive, aside from all the waiting and that's no surprise as the NHS is so stretched but the care that I've had I can't fault. Everyone's been amazing really.

47. Unfortunately, I did have to fight to be seen by a Rheumatologist to begin with, then had to wait seven months for treatment but once I was seen by the right people I was treated very well. Mr King was really good but he didn't tell me about contamination of others or managing bleeds.

48. It wasn't until I started seeing Marie Moore (who preferred to be called Teresa), the Hepatitis C specialist nurse, at the Royal Free and then at Hemel Hempstead that I was given information about not sharing razors or toothbrushes and everything else.

49. Honestly, Theresa Moore was so good but I needed to see her earlier on. It was great once I got there but I needed the information sooner. Unlike the cancer specialist there's no care straight away, just lots of waiting for referrals with no information.

50. I have never had any counselling. I was never offered any. I didn't even know there was any

mental help available.

51. Other than above, I am generally happy with the treatment, care and support I received.

Section 7. Financial Assistance

52. I received the Skipton fund initial payment of £15,000. I am still in receipt of the £500 winter fuel allowance paid each December by the old Caxton fund and I have the £1,500 monthly payment under the new English Infected Blood Support Scheme ("EIBSS").

53. The Royal Free gave me a number to call right at the very beginning of my illness but when I rang they told me they were only dealing with Scotland. I'm not the sort to claim for things usually but the specialist nurse, Theresa Moore, told me about the Skipton Fund.

54. I applied to the Skipton fund myself. I forget what the forms were like. My application got rejected at first because my medical notes had been mislaid when Hemel Hempstead Hospital partially closed. With my notes gone it was so hard to get proof that I'd had the transfusion. I was desperate. It cost me £50 to get the notes, which isn't much but at the time it really bugged me. The stress of them being lost was enormous, I started to think, am I ever going to prove it?

55. I was lucky, one of the nurses remembered me and told me that she still had the contact details for my spinal surgeon's secretary. Mr Hirschowitz had retired to South Africa but I emailed his secretary who managed to get hold of him. I asked him for the date of the operation as I thought it might be enough proof without my medical records. He was devastated to hear about my infection and I got a really nice email from him to say how sorry he was. Unfortunately, I still needed the medical notes.

56. I didn't pay the £50 until they found my notes. They had been lost for six months when I eventually got them. It was quite a fight, which I

found very stressful. In the end I had to go through pals at the hospital to find them. I went to the person who is in charge of record keeping at the hospital, she did the research and it took her a long time to find them. She said they had been stored in a hanger somewhere. Once I had them, I reapplied for the Skipton fund and my application was approved.

57. I found Nick at the Skipton Fund was not very understanding, he was a bit off and there was a complete lack of understanding from him about my medical records. It was sort of cut and dried that they needed the evidence and there was no understanding that it wasn't my fault I didn't have them. I had to go through the paperwork and reapply when I had the notes but now it's changed over they're really good.

58. The Caxton to EIBSS change-over has gone pretty smoothly and they've said they're continuing the £1,500 payments for at least the next year.

59. I now get the Personal Independence Payment ("PIP") but that was another big suffering really. I also got a mobility car. The PIP was a nightmare because they refused me the first time around. A male nurse came out to interview me for the PIP thing and decided I didn't qualify.

60. I lost my mobility allowance and it took six months with no money before I eventually got a court date to go to Watford to appeal it. My GP wrote putting my case and they changed their mind and allowed me the money. I've got it until 2023 now. There's total lack of understanding by them of what you've been through.

Section 8. Other Issues

61. I am appalled that the government allowed this to happen. I learnt from publicity on the news that these government ministers had covered it all up and I was shocked. I recognise it must

have been a difficult situation, if they were short of blood obviously they had to get it from somewhere. But, couldn't they have been more selective about where they got it from rather than resorting to American prisoners?

Statement of Truth

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

Signed GRO-C

Dated 2/5/19