Witness Name: Lindsey-Jayne Gregory
Statement No.: WITN4365001
Exhibits: NOT RELEVANT
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF LINDSEY-JAYNE GREGORY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5 October 2020.

I, Lindsey-Jayne Gregory, will say as follows: -

Section 1. Introduction

1. My name is Lindsey-Jayne Gregory. My date of birth is GRO-C 1966 and I reside in East Sussex. I am married with 3 adult children; 2 daughters and a son. My son was born in 1995 and my daughters were born in 1987 and 1988.

2. I work as a driver for an engineering company and travel all around the south of England with my work.

3. I am sure that I was infected with hepatitis C after undergoing surgery for third degree burns in 1982.

4. I intend to speak about my infection with hepatitis C. 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 our lives together.

Section 2. How Infected

5. I was infected with hepatitis C by receiving plasma and whole blood transfusions after I underwent surgery for third degree burns in 1982. The burns I received were the result of an accident I was involved in.

6. On the 7th November 1982 I was in Covent Garden with my family watching some buskers. I remember that it was the 7th of November as it was just after bonfire night. It was around 4pm in the afternoon and it was just starting to get dark. I was 16 at the time.

7. The buskers had torches to light the stage which were filled with paraffin. One of the buskers finished their act and the next performer refilled one of the torches with petrol, and it exploded. I was standing in the front row and the flames hit me.

8. It was a stupid decision but I don't think the busker realised the impact of refilling a torch with petrol rather than paraffin.

9. I suffered third degree burns to 40% of my body. The burns were mostly on my legs.

10. My Dad attempted to put out the fire on me with his hands and he was also burnt quite badly. My sister was standing next to me and her hand was burnt.

11. I was taken to the A&E at St Thomas' Hospital in London. I'm not sure what treatment I received there. There is no record of my treatment at the Hospital.

12. I was then moved to the McIndoe burns unit at the Queen Victoria Hospital at East Grinstead, West Sussex. I'm not sure if I stayed at St Thomas' overnight before being moved, or if I was moved on the same day that I was admitted to St Thomas'.

13. I spent 6 weeks at the Queen Victoria Hospital. During my stay there I had two skin graft operations where I received several plasma transfusions. My Mum also remembers me receiving blood transfusions. I don't remember the name of the surgeon who treated me at the Queen Victoria Hospital.

14. At the time that I was given the skin graft operations I did not know about the risks involved with receiving blood products. No one ever told me that you could get an infection from a blood transfusion. There was no information given to my parents or myself about the risks involved or about infected blood.

15. After six weeks of hospitalisation they let me out early for Christmas. My Mum was a nurse so she was able to change my dressings at home.

16. I did not receive any blood products subsequent to the skin graft operations and I had never received blood products on any other occasion prior to the burns incident.

17. I had a hernia operation when I was around 8 years old and I had my tonsils out in the 1970's, but I didn't receive blood.

18. I have never been an injecting drug user, and the only tattoo I have is one that I got very recently. Therefore, there is nowhere else where I could have contracted the infection.

19. I resumed my normal life after the operations. When I was around 17, I started experiencing a deep pain in my shoulder, which went on for years, but at that particular time it was quite acute for about 18 months. I went to my GP in Slough and it was diagnosed as muscular. I was given anti-inflammatories and the pain eventually eased off.

20. When I was diagnosed with hepatitis C, I was told that the pain in my shoulder was referred pain that was associated with the hepatitis.

21. In 1995, when my son was about 10 months old, I went to start giving blood again. I had given blood previously, but at that point in time I had not given blood in about 8 years. I had given blood on several occasions subsequent to the accident in 1982.

22. I received a letter 6 weeks later from the Blood Transfusion Service informing me that I should make an appointment to see my GP because I had tested positive for hepatitis C. The letter also instructed me to stop giving blood.

23. My GP, Doctor Dilley, confirmed that I had hepatitis C and referred me to the Royal Devon and Exeter Hospital. I was living in Devon at the time.

24. At the time of my diagnosis in 1995, I had heard of hepatitis more generally, because someone I know had contracted hepatitis whilst on a camping trip. I knew at that stage that you could get some kind of hepatitis from infected water, but it was not something that I had come across myself.

25. Doctor Dilley was always lovely. Hepatitis infection was not something that he had dealt with in his little doctor's surgery in Devon, it was as new to him as it was to me. He didn't know much about it, none of us

did. He always said that if I had any concerns I could come back and see him.

26. At the Royal Devon and Exeter Hospital I was placed under the care of Doctor Ruben Ayres, a Consultant Physician and Gastroenterologist.

27. He too was lovely. He told me that there was a treatment for hepatitis C called Interferon. He didn't really give me much information about Interferon, he just gave me the basic outline and referred me to a specialist nurse who we referred to as the 'The Interferon Nurse'. No one really seemed bothered about where the hepatitis had come from.

28. Doctor Ayres advised me not to bother having my husband and children tested, which at the time I thought was a bit strange. I was told that it was too traumatic to take blood from children and I accepted this, as back then you kind of just trusted the doctors.

29. GRO-C

30. I was told that the infection could be transmitted by blood, but they didn't give me enough information. If they had given me enough information, I think that I would have insisted that my children be tested there and then. I feel that I was largely left on my own to research the disease and treatment, and we didn't have the internet in those days.

31. The Interferon Nurse was the person who gave me the most information. She said that the Interferon treatment was horrible. She was the only specialist Nurse that I had access to and she left just as I was about to start my treatment.

32. She gave me some leaflets about hepatitis and Interferon, but overall, she probably did not give me sufficient information. I don't think she had that much information to hand, really.

33. I was told that the genotype of hepatitis C that I had was the least likely to be symptomatic, however it was the most resistant and the most difficult to get rid of. I wasn't initially told what genotype that I had. I later found out that I had genotype 2b.

34. I had a 12 month course of Interferon. The treatment consisted of me injecting myself with the Interferon at home three times a week

35. I completed the 12 month course of Interferon and the treatment was a success.

36. I was not prescribed Ribavirin tablets. The combination Interferon and Ribavirin treatment was still experimental when I began my treatment, and was for patients for whom Interferon did not work. I was told that if the Interferon treatment did not work for me, I would be started on the combination Interferon and Ribavirin treatment.

37. My liver function has always been good and there was never any liver damage. That is probably because I was always teetotal. Obviously, I had a binge as a teenager every now and then, but I had been teetotal for years before I was diagnosed with hepatitis C.

38. After I finished the course of Interferon, the Hospital discharged me. I then moved to Brighton and started seeing a Consultant at The Royal Sussex County Hospital.

39. I had my final appointment at The Royal Sussex County Hospital in 2003. My final blood test showed that I had no detectable hepatitis virus. I was discharged from the clinic with no further follow-up.

40. it never occurred to me that I could have contracted hepatitis from the plasma and blood transfusions. I didn't know where I had got the infection from.

41. I do not have access to all of my medical records. The records my GP has are not complete. All of my records before 1995 are missing. This includes the records of being burned and the treatment I received, and the records of me giving birth to both my daughters.

42. The records of my treatment at Queen Victoria Hospital were destroyed. I was informed by the Hospital that it is trust policy that health records are routinely destroyed if 8 years have passed since the most recent patient discharge date.

43. The Hospital did, however, find a record card advising them of my historic hospital record number. There is a letter and an email confirming that my medical records were destroyed.

Section 3. Other Infections

44. As far as I am aware, I did not receive any other infection besides Hepatitis C.

Section 4. Consent

45. I do not believe that I was ever treated or tested without my consent, without being given adequate or full information, or for the purposes of research.

46. My parents would have consented to the skin graft operations and subsequent plasma and blood transfusions for my survival. I assume

that at the time of the operations, they must have signed the appropriate forms for me to be given the treatment I needed.

Section 5. Impact

Physical and mental impact of hepatitis C

47. Growing up, I was unusually tired all the time. My mum would say, "she's always in bed, this kid".

48. As I mentioned previously, I had acute shoulder pain which I later found out was associated with hepatitis C.

49. I was 28 years old when I was diagnosed with hepatitis C. I had a husband and 3 children by that point. The mental impact of my diagnosis was awful. I got very paranoid about things being clean in the household and this caused me a lot of anxiety.

50. I would worry about everything. Whenever I got a paper cut I would be very anxious.

51. There was a fear that I had infected my children. I learnt through my own research that the infection could be transmitted by birth, GRO-C GRO-C GRO-C.

52. If they cut themselves, it was worrying. By way of an example, if I cut myself peeling potatoes, I would have to throw out the whole bag of potatoes.

53. When I was initially diagnosed, I was working as a Care Assistant. I did tell one of my Managers about my diagnosis as I had to be extra careful at work. It just affects everything. She was lovely about it.

54. I knew that they couldn't dismiss me because of my diagnosis as I had researched it. I also knew they were meant to be confidential and discreet about it.

55. It impacted everything for me, as I thought that I had to tell people about my infection, even though I didn't need to. I don't mind telling people about it now, but it has taken a long time for me to get to that point.

Physical and mental impact of the treatment

56. The 12 month course of Interferon was the most horrendous year of my life. I experienced flu-like symptoms. It was like having the flu every week.

57. Just as I would feel better, I would have my next injection and I would feel like I had the flu again.

58. I was very tired and lethargic and felt like I could not get out of bed to do my everyday tasks, such as taking the kids to school. I couldn't have the curtains open as the light hurt my eyes. I pretty much spent the year in bed.

59. I experienced fever, aches and pains, headaches and I was desperately tired all the time. I just generally felt really, really rough.

60. The Doctors were very encouraging, but the Interferon Nurse had left by then. The Doctors advised me that the treatment was my choice and that no one could make me have the treatment.

61. I was told that I would feel a bit bad and a bit fluey with the treatment, but they never told me it would be a rough year.

62. I also experienced depression. I had been slightly depressed previously and been on a short course of antidepressants, but with the Interferon treatment I felt really, really low. I have experienced depression a few times since finishing the Interferon, but I assumed that it was something else as I was clear by that point.

63. It got to the point where I couldn't sleep or eat. I would get into a cycle of being really tired, then being unable to sleep, and it was one of those downward spirals. However, I always went to the Doctor when I was experiencing these symptoms and found the right short-term antidepressants. They worked and I eventually got my sleep cycle back to normal.

64. No one told me that depression was a side-effect of the treatment.

65. I would sometimes become a bit grumpy and I did a lot of crying.

Impact on family members

66. At the time that I was receiving the Interferon treatment, my husband was working full-time and looking after myself and the kids, and we did not live anywhere near family. The children had a lot of fish fingers and chips during that time as I was always too tired to cook.

67. The children were too young to understand what was going on and they thought that I was just a bit of a clean freak.

68. My husband was a complete saint. Our relationship was a bit stressful for a while, but there was never a danger of us splitting up. It was a very stressful time.

69. When the kids were little and I was receiving treatment, we just kept our heads down and waited until it was all over. Our whole life was on hold at the time. There were no holidays, no meals out, I don't think that I even went to the beach with the kids that year.

70. They have never said anything about it though, they are too lovely.

71. It's only now, looking back, that I can see how bad it was for them. At the time I was so low, I didn't care.

Stigma

72. At the time, I lived in a little village in Devon called GRO-C and it was tough as we had just moved there and I didn't know many people.

73. It was one of those small villages where everyone knew each other and it was tough as being infected was not the sort of thing that you tell people.

74. I think that people thought it was all about HIV, it was all sort of lumped together as the same thing back then. HIV was the gay disease and hepatitis C was the drug user disease. This is what people thought, especially in Devon. There was a lot of ignorance.

75. Two of my very close friends knew about the infection, but no one else did. I kept it a secret because of the stigma attached to it.

76. I didn't go to the dentist for many years to have treatment as I knew how I would be treated. I now have false teeth as a result.

77. In the very early days of my diagnosis, I went to a dentist and did not tell them about my hepatitis, as I did not know that I needed to tell them. If it was any other condition I would have found out whether or not I needed to tell them, but being hepatitis, there was a shame a stigma attached to it that prevented me from asking.

78. Today it doesn't really affect my social life, but back then, when I was diagnosed, I was much more cautious in my social interactions, especially since I lived in a small town.

79. When I was initially diagnosed, and attended the Royal Devon and Exeter Hospital, I noticed that they were not too bothered about my diagnosis. However the next time I attended, I noticed that there were big yellow warning stickers on my patient file which read 'danger of infection'. I also began to notice that they would gown up when I was being seen.

Financial impact

80. During the time that I was receiving the Interferon treatment, we were surviving on benefits as I could not work due to my condition. My husband was working full-time, but at a minimum wage job, and we had 3 children to support.

Section 6. Treatment/Care/Support

81. I was never offered any counselling or support, except for the Interferon Nurse, who left shortly after I commenced my treatment. She was not replaced.

82. She was the only person who said that if I needed someone to talk to I could call her. No one else really offered any support. They would answer questions but they were not very forthcoming. I think that's just the NHS for you. They are always so limited as for time and they just tell you what you need to know.

83. I didn't even know about the Hepatitis C Trust until I started researching the Skipton Fund. I then got the details I needed to make an application to the Skipton Fund from the Hepatitis C Trust.

Section 7. Financial Assistance

84. I learned about the Skipton Fund from a girl at the cafe I was working in at the time. I did not know about it prior to then. There was a hepatitis C support group meeting in the room upstairs and the girl was a regular at our cafe who I would talk to often.

85. I submitted an application to the Skipton Fund with the medical records that were available to me. As I mentioned previously, I was not able to access all of my relevant medical records as some of them were destroyed and the remaining relevant records after 1995 are missing.

86. I informed the fund about this and they told me that my GP surgery would need to confirm to me in writing that my records prior to 1995 are missing. I would then have to send a copy of this confirmation to the fund.

87. To date, I have not received any payment from the fund. I was never told that my application was unsuccessful. I was just told that the application process was an open ended thing and that it could go on as long as it needed to.

88. The last time I emailed the fund, I told them that I had not heard back from them since I sent the letter from my GP. I did not receive a response from them. This was 2 years ago.

89. I gave up as no one was responding to me, so I thought it was a case of there being other people that were more deserving.

90. I feel as though the Skipton Fund has ignored me. They never once reached out to me to see how I was getting on. I was always the one who had to contact them.

Section 8. Other Issues

91. I feel like I am one of the lucky ones, as I was largely asymptomatic and I cleared the infection. I have attended a few support groups and there is always someone who is worse off than myself. There are lots of people who are still suffering, who have had all of the treatments and they have failed. Some have even been crippled.

92. I'd like to be sure that something similar couldn't happen again. I hope that lessons have been learned and are still being heeded. I think that someone needs to be held accountable.

93. It is not about financial compensation for me, I'm more worried about the fact that this has affected so many people. For me, giving this statement means that I am included and my voice is heard. It is a positive for me and means that people are being heard.

94. I think it is terrible that they knew about the infected blood and did not tell everyone as soon as they found out.

95. Everything feels really brushed under the carpet and hush hush. I don't think that the thing about the medical records going missing was a

coincidence as I have spoken to so many people whose medical records have also gone missing. It has happened way too many times for it to be a coincidence.

Statement of Truth

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

Signed GRO-C

Dated 18 November 2020