Witness Name: Sarah OGLE
Statement No.: WITN0126001
Exhibits: Nil
Dated:

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SARAH OGLE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 1 November 2018.

I, Sarah OGLE, will say as follows: -

1. Introduction

1. My name is Sarah OGLE. My date of birth is GRO-C 1969 and my address is known to the Inquiry. I am 49 years of age and live in Liverpool with my partner of 23 years.

2. I intend to speak about my experience of receiving infected blood transfusions as a teenager, contracting Hepatitis C and my subsequent treatment.

2. How Infected

3. I received blood transfusions at Liverpool's Alder Hey Children's Hospital while undergoing spinal surgery for treatment of spondylolisthesis in 1983 and scoliosis in 1984.

4. In approximately late 1991, I was informed by a letter from the South West Blood Transfusion Service telling me to contact them. I remember the letter being unclear except for saying that I'd been routinely tested for viruses including Hepatitis C and HIV Aids. At the time, I was studying at a college in Exmouth and gave blood a total of 2 or 3 times.

5. I was told I had antibodies that could be Hepatitis C and that I would be required to undergo further testing. I had an appointment for more tests and completed a questionnaire, which included questions about whether I had ever used drugs and my sexual history; quite frightening and intimidating for a 21 year old. At this point in time, I was not told whether I had contracted any of the viruses they were testing me for; however, I was given a very basic fact sheet which covered Hepatitis B, Hepatitis C and HIV. I was then referred to Dr T K Daneshmend at the Royal Devon Hospital.

6. In March 1992 tests confirmed I had antibodies relating to Hepatitis C but the doctor made me aware that it didn't necessarily mean I had the virus. He suggested my blood transfusions when I had my back surgery could be the source.

7. I don't remember receiving much information other than that I could infect other people, so I needed to avoid sharing toothbrushes, having unprotected sex and be careful if I cut myself. It was hard to comprehend as while they were telling me it wasn't HIV and not to worry, all the signals and advice were consistent with the messages around that infection which was making headline news.

8. After a short spell back home in Liverpool I moved to Manchester and was passed into the care of Wythenshawe Hospital.

9. In 1995 tests confirmed that I was positive for Hepatitis C and negative for Hepatitis B but may have viraemia. It was reiterated that I needed to avoid sharing toothbrushes, having unprotected sex and to take care in case anyone else came into contact with my blood.

10. The doctor questioned my mum about whether the virus could have been passed on from her, asking probing questions about her lifestyle and medical history. GRO-C I was sent for a liver biopsy.

11. Mum was devastated at the thought it might be her and its potential implications for me and my younger siblings. She described the period from the questions GRO-C GRO-C as *"living in a daze with a constant lump in my stomach at the possibility it was my fault"*. Mum had some medical knowledge and understood the long term consequences. It was also a huge worry for my Dad who had preconceived ideas of what the future might hold, medium and the long term implications; the stigma of a 'chronic liver condition' assumes it's the person's fault. I've always found that difficult to cope with that assumption, especially when I've had to tell people close to me.

12. GRO-C

13. I had a number of routine checkups with regular liver functions tests and then in 1997 was told in a very matter of fact way that there were some changes in my results and was referred to Royal Liverpool Hospital where there might be treatment available.

4. Consent

14. My parents recall that they did not give consent to the blood transfusions I received during my spinal surgeries. They recall that they were told that the operations would be long and that I would be in hospital for a few weeks. At that time you weren't encouraged to ask any more.

15. To the best of my knowledge, I did not give consent for any testing relating to Hepatitis C or HIV. I received a letter noting that I had been routinely tested for viruses including Hepatitis C and HIV Aids. I think I was tested as I had donated blood whilst I was at a college in Exmouth.

16. I don't believe I was treated without my knowledge.

5. Impact

17. There were no real obvious physical effects of being infected until my treatment but I would say the mental impact has been significant at times.

18. The confusion and uncertainty around what the first diagnosis meant in the short, mid and long term was particularly difficult as I was living a long way from home. The fear of 'other people finding out' was huge as was the guilt of 'what if my blood has infected other people'. The latter is something that still causes me anxiety.

19. At the Royal Liverpool Hospital, Interferon was discussed as a possible treatment. There was only a 50/50 chance of it being successful but I felt I had nothing to lose and on being asked if I could give up alcohol, I was happy to do so. The treatment was explained as self-injecting 3 times a week, which panicked me at first as I'm not good with needles. I would always think of my friend's partner who was diabetic and had to inject every day to live, so what was 3 times a week for a year? She was a huge inspiration!

20. I began Interferon treatment in 1997. The injections were hard; trying to time them so I felt my worse away from work wasn't always easy as I worked many evenings. I was at that time working in GRO-C and lived in a bed & breakfast during the week, I was grateful for the family who looked after me; always ensuring I ate well and was warm. Physically I felt like I had flu on and off for the whole year and some days it was a struggle to get through it; my body would ache and my head would feel wooly. Paracetamol and grapefruit lucozade helped get me through as did thinking about all those who weren't getting the opportunity to have the treatment and how fortunate I was.

21. While in hospital for my back operations, my Mum had always encouraged me on my down days that there were always others worse off than me and I should be grateful. I kept focusing on this thought despite feeling as I did. Weekends during this time were either spent travelling home to be with my parents or visiting my partner in GRO-C. He was working and studying for an MBA at that time and the year was a blur for us both. In some ways, that we were both

dealing with challenging times strengthened our relationship. Friday injections were always taken once I arrived at my destination as weekends were the hardest; I felt physically and mentally exhausted.

22. Travelling also induced fear as I would have a large yellow sharps box for used needles in my bag. What if someone saw it? What would they think? How would I explain? The stigma attached with those boxes and the disease at that time was a huge cause of anxiety.

23. In approximately 1998 I had a regular check up at the dentist, who asked how I was and out of courtesy I felt I should tell him I was being treated for Hepatitis C. His response was that he refused to treat me any further and that I was a risk to him, his staff and his patients. I was shocked by such a response; surely he would understand and what about all those people he treats and he doesn't know what conditions they might have! I was told I could only be treated at the dental hospital and that put me off going for a long time.

24. Throughout early diagnosis, my treatment and to some extent still today I feel anxiety and anger at the lack of understanding about the virus. Many jump to conclusions and have perceptions that I was a risk. Thinking carefully about who has to know or not was always difficult especially in a work environment. For example who needed to know in case I cut myself and explaining why I didn't drink. The latter was particularly difficult to navigate as I work in a profession where a drink is part of the role. I work in marketing in theatre and if you met journalists, you would often have a drink, you'd toast a show opening with a few drinks and it can be a very social and late night environment.

25. I'm fortunate that the treatment worked and was discharged from the hospital in 2000.

26. I have suffered from depression and anxiety on and off since my late teens. In 2006-2007 after a particularly difficult period my Doctor recommended Cognitive Behavioural Therapy ('CBT') and I visited a counsellor. This covered dealing with a number of issues - being bullied at school and work stress, but more importantly the impact of my back operations and HCV diagnosis &

treatment on me and my family. I felt particularly guilty for the impact of my operations and HCV on my Mum's mental health.

27. Although clear, I still have significant deep down anxiety that it will return or that I may have some long term issues. Worse, that I may have passed the virus on through the blood I donated all those years ago and that person or people may not be so fortunate in successful treatment. Although I don't think I've ever been keen to have a family, my buried anxiety around this has I believe fed into my choices.

6. Treatment/Care/Support

28. When I was first diagnosed there didn't seem to be any support; but I think that was just the times and the focus being on the HIV virus.

29. I was offered support when I was undergoing treatment but it was just, 'here's a nurse you can talk to and a leaflet about the British Liver Trust'. It was all very matter of fact and almost like they were doing me a favour; again a sense that it was probably my fault I had the virus.

30. I recall that the leaflet had a support number to call, but I never did. I was always worried that the more I knew, the harder it would be. What if I had HIV too? In the early days of my diagnosis, I really just wanted to live life to its fullest, finish university and get a great job in a theatre. I buried the knowledge and fear that I could become seriously ill and die young very deep for many years.

31. An offer of counselling or psychological support was never clearly apparent at any stage. It was only on receiving my CBT in 2006-07 that I realised what a huge psychological impact the infection had on me and to some extent still does today.

7. Financial Assistance

32. I think my Dad read about financial assistance in the paper and I looked into the Skipton Fund. I was unsure it was appropriate for me to apply as I was physically well but my parents encouraged me to; especially after all the treatment and on-going mental impact. I think the last few months have actually been harder trying to get this statement together.

33. The first application was returned as I didn't have 'proof' it was a blood transfusion; suggesting I access my medical records. Alder Hey Children's Hospital didn't have my records, which I think is normal after such a long time gap. My doctor provided copies of some letters of correspondence from the hospitals and of the notes of my surgeries, signing off the application.

34. I received a first stage ex gratia payment of £20,000 in 2011. I've never really earned much money in my job and at the age of 42, the money served as a deposit for the house I now share with my partner. In recent years I have been in receipt of quarterly payments of approximately £1,000 from the England Infected Blood Support Scheme.

Statement of Truth

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

Signed GRO-C

Dated 18.04.19