Witness Name: Elaine Turner
Statement No.: WITN2702001
Exhibits: WITN2702002-WITN2702004
Dated: 3 April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ELAINE TURNER

Section 1. Introduction

1. I, Elaine Turner, will say as follows: -

2. My date of birth is GRO-C 1962. My address is known to the Inquiry.

3. I live with my husband in Gloucestershire. We have three children, one of whom still lives with us. I no longer work but in the past have held various roles, including in accounts, retail and as a teaching assistant. My husband works full time.

Section 2. How Infected

4. I was induced for the birth of my second child on GRO-C 1989 at Wexham Park Hospital, Slough. After my daughter was born, I was told I had retained placenta products which needed manual removal, causing blood loss. As a result, I was given a blood transfusion whilst under general anaesthetic. I

didn't know about the transfusion until after I came around after the operation, and when I came round they told me I had had a blood transfusion. I was aware of the risk of HIV from blood as it had been in the news very prominently during the 1980s. I knew the wife of GRO-A, had died after being given an HIV infected blood transfusion during the birth of her first child. I raised it with the nurses asking, 'is that blood alright?', and they said all the blood had been tested.

5. I was not given any information or advice beforehand about the risk of being exposed to infection because I was under general anaesthetic, however, I did receive the assurance afterwards that the blood was tested for infection.

6. As a result of being given infected blood I was infected with Hepatitis C (HCV).

7. I found out I had been infected with HCV seven years later in 1997. I had my youngest child, a daughter, in GRO-C 1996. The GP called me around Christmas time and asked me to come into the surgery for a routine blood test. I thought it was something to do with having just given birth. I went in for the blood test and asked why it was necessary and the GP told me it was part of the Look Back programme. I asked what the programme was for and he said it was to do with batches of blood. He told me he didn't think I had anything to worry about and said to enjoy the holidays and that he would call me with the results.

8. Six weeks later I got a telephone call from the John Radcliffe Hospital in Oxford and a specialist asked if I was sitting down and said to me that she was really sorry to tell me I had HCV. The specialist told me that HCV is a virus that attacks the liver and could potentially cause liver cancer. I asked if I was going to die and she said no, that they would do everything to help me.

9. I was not given adequate information to help me understand and manage the infection when I was first diagnosed. It was 1996 and the internet was not as

useful as it is today. I found out what I could online and ordered a book from the Hepatitis C Trust, which is where I found out most information.

10. I believe that information should have been given to me earlier. I think the GP knew what he was testing and I think I should have been told at that point.

11. I am dismayed about how the results of the tests were communicated to me. Although I was asked whether I was sitting down, that was all. I was in the house on my own with my new baby and my older two children were at school. I thought they could have called back when my husband was there so that I had some support.

12. At this point I was given no information about the risks to others of being infected. I was completely shocked and overwhelmed and didn't think to ask questions. I was given an appointment at the John Radcliffe Hospital for the following week, in February 1997.

13. I have recently obtained copies of my medical records and can see that a letter dated 24 February 1997 from the John Radcliffe Hospital to my GP (**WITN2702002**) confirms how they believe I came to be infected:

'Thank you for referring this lady who was found to hepatitis C by the Lookback series. She has transfused with blood from a donor now known to be hepatitis C positive in GRO-C *1989. This was for post-partum bleeding. She has no other risk factors for hepatitis C and she is asymptomatic.'*

This letter goes on to note that the doctor explained to me the risk to others at this appointment.

Section 3. Other Infections

14. I do not believe I have received any infection other than HCV as a result of being given infected blood. I was extremely worried I had been infected with other infections, such as HIV, but I was tested and the result was clear.

Section 4. Consent

15. I do not believe I have been treated or tested without my knowledge or consent, or for the purposes of research. However, as set out above, I believe my GP knew what he was testing me for and chose not to tell me. When I went back to see him to get a prescription for Interferon after I had been diagnosed, he already seemed to know that was what I was there for and had got the prescription okayed before I even got there. He made a big show of telling me how much it cost.

16. I can see from my medical records that the GP did in fact know what he was testing for. **WITN2702003** is the letter dated 18 December 1996 from the Look Back programme to my GP and is actually titled, 'Hepatitis C Look Back Programme'. He evidently decided not to tell me what the test was for and I feel this was not right. At the end of the letter, in handwriting, is a note which says, 'a selection of leaflets about Hep C also enclosed'. I don't know if these leaflets were intended for my GP or for me, but I know I wasn't given any leaflets by my GP.

17. I have also seen correspondence from the HCV National Register in my medical notes (**WITN2702004**) asking my GP for updates on my status, including details of any further tests or treatment I had had. The letter says, 'It is important to note that we are still following up all patients, whether they have cleared the virus or not (either spontaneously or following treatment)'. I was unaware I was being monitored in this way.

Section 5. Impact

18. Before I was diagnosed I struggled with the symptoms of HCV without knowing what it was. I suffered extreme fatigue but put this down to being a working mother of young children. It wasn't until I looked into the disease that I found out that extreme tiredness was a symptom of HCV. I recall telling my GP

about the tiredness and being told, 'what do you expect, you have three children?'

19. When I was given the diagnosis I was shocked. I realised I had been living with the infection without knowing it for seven years and may have passed it on to my husband or children. My first thought was very I had passed it on to my tiny baby.

20. I also started to worry I had been infected with something else too, like HIV, and was very fearful of this.

21. I got upset quite a lot, and found myself feeling teary when I thought about it. I didn't have enough information and that was very difficult. My husband was very supportive and told me not to worry and to wait and see what happens, but he knew very little as well. I couldn't find out any more or do anything about it until I saw the health professionals. It was a very difficult time of waiting.

22. My baby daughter could not be tested for HCV until she was a year old. The GRO-A. My GRO-A GRO-A. It was a horrific experience. GRO-A GRO-A.

23. Shortly after being diagnosed I had a liver biopsy in July 1997 which showed some inflammation and early fibrosis of the liver. This meant the virus was affecting my liver but I was told the changes were relatively mild. I was offered treatment or told I could wait and see how things progressed. I chose to start treatment. The treatment I was given for HCV started in September 1997. I was told I had a very virulent form of the virus and received six months of Interferon and Ribavirin. The side effects were horrendous. I had to stop taking Ribavirin because I became very anaemic. I felt very sick and was

unable to eat. I lost weight and every time I attended another appointment my weight had dropped again, to the point where I became skeletal. I am five foot five inches and my weight dropped to seven stone. Each time I injected myself with Interferon I felt very low, suffered pain, fatigue, flu like symptoms, general aches, headaches, nausea, insomnia and sometimes diarrhoea.

24. At the end of the treatment in 1998 I was told I was cured. I was told I could forget about it all and get on with my life, but you don't do that. Even after treatment ended, because I had been part of a clinical trial, they wanted to know why it had worked on me and not on others. Every time I tried to put the infection out of my head they would contact me, asking for another blood test. It is never over. The infection is always at the back of my mind. Whenever I get ill with flu like symptoms or a health problem, like when I needed gall bladder surgery, I wonder whether it is the infection coming back. There is a chance that it could. Every time it comes back into the news, like with this Inquiry, it drags everything back to the surface for me and I get down thinking about it.

25. After treatment ended I was called back every few months to the hospital, then annually to see my GP for PCR tests and liver functions tests, and then every five years. I haven't received any follow-up for quite some time now. I have not had a repeat liver biopsy or scan since the ones I had before treatment started in 1997.

26. I am unaware of any further medical complications or conditions which have resulted from the infection or from the treatment I received for the infection. I have been unable to drink alcohol since being diagnosed as it brings out red blotches all over my skin. When treatment ended I experienced which I believe was linked to the treatment. I have also suffered with weight gain and heavier menstrual bleeding since treatment ended and think both may be attributable to the treatment, but this has never been confirmed. I have also undergone a cholecystectomy which may possibly be linked to the HCV infection itself, but again, this has never been confirmed.

27. I did not face any difficulties or obstacles in accessing treatment. When I was offered treatment it was still in the clinical trials phase and the medical professionals were very forthcoming, explaining that the treatment was hit and miss.

28. I do not know whether there were treatments which I ought to have been offered but was not. I knew of no other alternative at that time.

29. The mental and physical effects of the treatment I received were extreme, as described above. I think that is the only time in my life that I have been depressed. When asked how I felt I said I was feeling very down, very miserable and would love to stop the whole thing. I received no monitoring of my mental health.

30. Sometimes I believe my infected status has impacted upon my medical treatment and dental care for other conditions. For example, after I told my dentist about the infection, as I felt I should, my dentist made me the last appointment of the day. Although I could understand why he did this, I felt humiliated.

31. The impact of being infected with HCV on my private, family and social life has been difficult. My husband and I had separated just before the birth of my second daughter in 1996. We got back together shortly afterwards and, with hindsight, we wondered whether the arguments we were having may have been a result of the exhaustion I was experiencing, a symptom of the HCV. I have known my husband since I was 18 years old and he has been very supportive throughout.

32. My mother was still alive at the time I was diagnosed with HCV and she saw the effects of the diagnosis on me. I was the youngest of seven children, I was her baby. She didn't understand the disease and took a long time to come to terms with it. She struggled to understand that her child had been infected,

perhaps knowingly. She worried about me a great deal and I saw her cry a few times.

33. The infection and treatment meant I missed valuable time with my children when they were young. They didn't know at the time what was wrong, just that I was very ill. Now that my children are older they understand more and are very angry about what happened to me. My middle child blames herself because I became infected at the time of her birth. She is now 30 and has said to me that if she had not been born I would not be ill. The first time she said this was when she was a teenager and it was very painful to hear her say that. I try to tell her it is not her fault.

34. At the time I first learnt of the diagnosis I told very few people. I only told a few close friends because many didn't really understand. When I said I had had a blood transfusion which was contaminated with HCV they asked if it was like AIDS. When I said no, they would say, 'well that's alright then'. I think they thought it wasn't fatal and so it was ok. That was very hard to deal with.

35. My employer at the time was very unsympathetic and, when I told him, he said, 'if you bleed you can clean it up yourself then'. Thankfully, though, my employer did not tell other employees at the firm. When I was going through treatment I was trying to find another job and felt I had to tell prospective employers so I would be able to ask for time off work because of the treatment. I was honest about the infection and treatment and failed to get a single job, even those I was overqualified for. I ended up leaving the job I was in anyway because the treatment made me so unwell I could not work.

36. Financially the infection has had an impact on my life because I have had to give up work and have lost my income. We moved to a new area and I looked for work again, though decided not to tell any prospective employers. I did eventually manage to find a job and then told my employers about the infection and that the treatment had cleared it.

Section 6. Treatment/Care/Support

37. I have never been offered counselling or psychological support in consequence of being infected.

Section 7. Financial Assistance

38. I received a letter from the Skipton Fund saying they were giving me a pay out of £20,000. Two years ago the Skipton Fund, now the EIBSS, started making annual payments of £3,500 per year, which is now just over £4,000, plus the winter fuel payment.

39. The financial assistance offered is not enough. It makes no comparison to what I was earning before I became ill, and now it is over twenty years later.

Section 8. Other Issues

40. I hope the Inquiry is able to find out who is responsible for what happened and hold them accountable. I believe people knew the blood was contaminated yet they still gave it to people. The only person who has ever said sorry to me is the doctor at John Radcliffe Hospital.

41. I hope the Inquiry is able to achieve justice for those infected and affected, with more meaningful financial assistance and compensation.

42. I want the Inquiry to make those responsible understand the effect this disaster has had: I still find it very difficult to think about the infection, it is there all the time and I have to live with that forever.

Statement of Truth

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

Signed

GRO-C: Elaine Turner

Dated 5 April 2019