Witness Name: Sharon FARMER
Statement No: WITN3982001
Exhibits: WITN3982002 - 8
Dated: 18th March 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF SHARON FARMER

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 24th January 2020.

I, Sharon Farmer, will say as follows: -

Section 1. Introduction

1. My name is Sharon Farmer. My date of birth is GRO-C 1955 and I live in GRO-C, Cornwall. My full address is known to the Inquiry. I used to be a health care assistant, but I am now retired upon the advice of my doctor. I have one son, Timothy aged 43, who used to live with me until last year, and I now live by myself.

2. I intend to speak about my infection with Hepatitis B (HBV), which I contracted as a result of my treatment for chronic myeloid leukaemia in between September 1993 and April 1994.

3. In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment I received and the impact it had on my life and my family.

4. I am not legally represented, I am happy for the Inquiry team investigators to assist me with my statement.

Section 2. How Infected

5. I have always been a relatively healthy person. I had some general health problems as a child, like allergies and asthma and one nasty case of viral meningitis. None of the illnesses I did have were long lasting or very severe. I have always been a strong-willed person when it comes to illnesses, I am afraid like most people, but I always try to carry on with life.

6. In the early nineties, when I was in my mid-thirties, I noticed that any colds and illnesses that I had picked up wouldn't go away quickly, they were hanging around a lot longer than they usually did. In March 1993, I was initially tested for going through early menopause because of the problems I was having with my health. As time went by, I found it more and more difficult to go to work and eventually I had to give up it for a little while because of how much my health had deteriorated.

7. My health problems were gradually getting worse. I remember a day in August 1993 vividly, I was bed bound and when I tried to get up I was in immense pain. I had to drag myself out of bed and when I tried to

walk I was bent over in pain, all from just getting up. The pain was horrific and I knew that there was something really wrong with me.

8. Shortly after that, while my son was at college, I had awful pains in my stomach and running up my torso and an unbearable headache. I couldn't move. I spent all day in bed because I couldn't get up, I couldn't go to the toilet or get a drink, I couldn't do anything.

9. When my son came back at about six o'clock that evening, I asked him to get me a glass of water. He didn't understand, I think he thought that I was just being lazy because I had been in bed all day. I took a drink of the water and immediately I felt it fizz up inside of me and I brought it all straight back up.

10. We called the doctor and Dr Connor came up from the GP surgery to see me. After he examined me he told me that he thought that I might have kidney stones, but then I overheard him talking to my son downstairs and he said "I think your Mum might have something in her blood". I didn't know what that meant at that time.

11. I was then admitted to Addenbrookes Hospital for testing. It came back that my spleen was fourteen inches long when it should only be about four inches. I knew then that there was something really wrong with me. I knew a lot about medical conditions from my care work and I started to think right then that I must have either cancer or AIDS.

12. After a few days, on 21st September 1993, Dr Marcus told me I had been diagnosed with chronic myeloid leukaemia. I had my suspicions because I had been moved to a ward where the majority of people were bald, but that diagnosis was frightening.

13. Everything started then, I was put on machines to try to clear me out and I had lots of scans. Then they put me on interferon but it became clear that it wasn't working and they put me on hydroxyurea capsules of which I had to take twelve every morning, midday, afternoon and evening. It was a horrible and exhausting time.

14. In 1994 I had to have five days of radiation for twenty minutes each morning and each afternoon, every twenty minutes when I had to stand there it felt like I was standing there for hours. I was given a special high protein milkshake to stop the radiation sickness but the radiation was still awful.

15. I was very lucky as GRO-C was a bone marrow match for me, I still can't believe now how lucky I was that he matched, GRO-C GRO-C

16. They gave me a strong intravenous dose of chemotherapy, and on 28th February 1994, he gave some of his bone marrow. By half past five that afternoon it was being given to me up until ten o'clock that evening.

17. After that, I had all sorts of infections come up while I was recovering, particularly graft versus host disease. There was a week where I just lay in bed and I had to have everything pumped into me intravenously, all of my medication, my food, water, platelets and marrow.

18. I was so vulnerable at that time as my immune system was pretty much non-existent. At some point, I don't know exactly when, I was given a pill to prevent me from getting Hepatitis B. I was very susceptible to infection and they needed to make sure I didn't catch anything.

19. I remember the day when the treatment started working so clearly. It was my 39th birthday, my son and my Mum were visiting and the nurses came in with a card and balloons, and they said they had some good news for me, they said that marrow had started growing. I was so happy.

20. I was discharged from Addenbrookes Hospital in April 1994, but I still had to go back in three times a week. Every time I went they would give me blood transfusions, platelet transfusions and all sorts of different medications intravenously. I don't remember how many

transfusions I had, it is hard to keep track of that sort of thing especially while you are in recovery and not back to normal yet.

21. I slowly recovered and eventually I became well enough to go back to work in 1995. Then, in November 1995, I became ill. I thought I had pneumonia and so I was admitted back to Addenbrookes Hospital. I had some blood tests and after a week Dr GRO-D came to see me.

22. He came to my hospital bed and he told me that I didn't have pneumonia, I have Hepatitis B (HBV) I was in shock. I couldn't understand. It was a horrible moment, especially as Dr GRO-D was a very abrupt man and he didn't tell me in the way in which I should have been told. They wouldn't let me leave the hospital but they also gave me no treatment for the HBV. I just had to wait there.

23. I didn't think much about what the HBV would do to me at that stage, because I am strong-willed, but I did keep thinking about how I got the HBV though. I knew what HBV was because I had worked with drug addicts who had it as part of my care work. I felt awful. I kept wondering how I had caught this infection, I'm not a drug addict, I just didn't understand how it was possible that I could get it at all.

24. No one would tell me how I caught it. They kept suggesting and kept trying to make out that I had got the HBV from sex. They didn't say anything about drugs, tattoos, or piercings and they definitely didn't say anything about blood, they only focused on it having been sexually transmitted. I knew that it wasn't possible, simply because there was no one in my life with whom I had that sort of relationship. It made me feel even worse.

25. I wasn't given any treatment for HBV, they didn't even tell me what effect it would have on my life in the long term. They didn't tell me about any adjustments I needed to make in my life or how to move on with my life. They gave me no guidance, not even about future sexual relations, they gave me no advice whatsoever.

26. Over the years, the HBV took its time to affect me. I have annual check-ups with Dr Hussaini and Liz Farrington at Treliske Hospital. They run blood tests to see if I am still clear of the leukaemia.

27. On 20th January 2016, my blood tests showed the HBV as present again, and they then referred me to the local haematology department at Camborne Community Hospital.

28. On 19th January 2018, I was found to have hepatic fibrosis, as exhibited at **WITN3982002**, but it wasn't until September 2018 that Dr Parker in the oncology department at Treliske Hospital said that something needed to be done about the HBV. She said that she could see in my notes that I had been given preventative medication, and she also said that she could see in my notes that the HBV had come from infected blood.

29. It took all those years for someone to tell me that. I am not happy about any of it but it was a relief that it was acknowledged and that I had an answer to my question of how I had caught the hepatitis.

30. They finally decided to treat the HBV by putting me on Tenofovir, as exhibited at **WITN3982003**, in September 2018. It was an awful pill. It was a big, blue pill the size of a horse pill and it was very difficult to swallow. I had to take it every day for two months. It made me very drowsy and it made me feel a lot lower than usual, I wasn't depressed but I found myself worrying more and having a lot more days where I felt low.

31. There were a lot of discussions about what to do, they were considering putting me on Tenofovir permanently. After two months, however, everything in my liver had stabilised and so they stopped giving it to me. I now have frequent reviews and scans of my liver to check the effect of the HBV.

32. I am still not clear of the HBV infection. My viral load is low but it is not low enough to be classed as undetectable, as exhibited at **WITN3982004**. All I have been told is that I have gone back to normal, as exhibited at **WITN3982005**. There aren't any plans at the moment to give me any more treatment and I don't know how long I will have to keep living with this infection.

Section 3. Other Infections

33. As far as I am aware, I have not received any other infection as a result of the blood transfusions. I have been tested for Hepatitis C, which came back negative. I think I have also been tested for HIV.

Section 4. Consent

34. I have consented to all tests and treatments, which I have had. I don't believe that I was tested or treated without my consent.

Section 5. Impact

35. After my diagnosis with HBV in 1995, I have experienced several different health issues. On 2nd April 2009 I was diagnosed with chronic kidney disease stage 3, which luckily has been classed as stage 2 on 18th October 2018, but I am still in continuous and a high level of kidney pain.

36. As the years have gone on, I have been put on a lot of long-term medication for various issues with my health such as, on 17th October 2018, I had a small stroke caused by my radiation treatment and a hysterectomy just after my 60th birthday. As I get older and more things

start to happen to my body, I worry that the HBV will have a greater effect on me if it flares up again.

37. My liver is stable now, following the two month course of Tenofovir, but before they decided to treat me, I was starting to suffer from some liver issues. As I mentioned earlier in my statement, I had developed hepatic fibrosis and in June 2018, a fibroscan showed that I had a bulky liver with fatty infiltration, as exhibited at **WITN3982006**. I am worried that even more damage will be done to my liver if the HBV infection does flare up again.

38. I very rarely drink. I only drink a half pint of Guinness very occasionally but I am more aware of drinking since my HBV diagnosis.

39. I have constant fatigue now, as exhibited at **WITN3982007**, which makes everyday life harder than it used to be. When my son lived with me, he would help with the hoovering and other bits around the house, now that he's gone I find all of these things difficult to do. I can get out and about but only because I make myself, it is hard but I know that if I don't keep myself motivated then I won't get out. I do have a walking stick and but I try to go out without it. I am not prepared to give up, I want to be able to go where I want and do what I want.

40. My fatigue forced me to cut my career short. I used to be a health care assistant visiting lots of different places but because of my extreme fatigue, I had to retire on medical grounds in 2015, as exhibited at **WITN3982008**. I didn't want to leave it at that time but I knew that I was getting to a point where I could only do so much.

41. This affected me financially as now my only income is from ESA capability disability payments and housing benefits, and I still have to pay the top up amount for the housing benefits as well. This has made things difficult and it means that I am not able to afford my own home like I had before, and instead I now have to rent.

42. It was difficult to handle the news of my infection with HBV because I didn't have a lot of support. I knew I couldn't turn to my family. I love my Mum dearly but she wasn't always there for me in times like these. When I was diagnosed with leukaemia, she didn't believe me or what the Doctors had said.

43. I knew that I wouldn't be able to get any support from her and I never told her about my infection with HBV.

44. I found it difficult to tell other people in my family about my infection with HBV because of how much of a shock it was to me. I had a really hard time processing how it could have happened to me, I really didn't know I could have got it when I wasn't the kind of person who normally got it. I only told my son and few long-term friends about it in the end, but I told them everything.

45. I haven't had any problems with stigma, no one has been nasty to me but I am very careful about who I tell about HBV and when I tell them, relationships have been particularly tricky as I don't want to tell someone and have them run away.

46. My infection with HBV has had a large impact on my ability to have a romantic relationship. I talk to people online and I do use online dating a bit, mainly because people don't socialise in the way they used to. The problem with online dating is that that you have to talk to a person for a while first just to make sure they are who they say they are, which creates the opportunity to get invested in someone.

47. I would like to have someone in my life, I would like to have that close relationship with someone but I know that I will have to explain everything to them and how I don't know what will happen in the future. I will have to tell them to let their doctors and dentists know that they are dating someone with HBV.

48. It is always in my mind that when I meet someone that they might walk away if I tell them. I know that they will have lots of worries in their minds too like 'is she going to die?' or 'will I catch something?', all of these thoughts are constantly at the forefront of my mind. You have to really and truly trust the person to tell them as well, which means that you will have to have a connection and that it will hurt if they do walk away. I don't want to be alone but I'm scared I will be because of the infection.

Section 6. Treatment/Care/Support

49. I have had to have all possible scans for my liver to check that it is healthy and that the HBV hasn't had more of an effect on it. I don't enjoy these scans, I get a strange clicking feeling whenever I have one. I have had to have liver biopsies as well, which thankfully they don't do anymore. They were always incredibly painful, it felt like a heart attack, it was a horrible sensation and experience.

50. I have been lucky with all of the GPs that I have had over the years, they have all been good to me. The only time that I had an uncomfortable experience with a doctor was with Dr **GRO-D** He had a horrible bedside manner and he was not the kind of doctor who should be delivering the shocking news of an HBV diagnosis.

51. I was never given much information about my infection with HBV, no one ever sat down and told me anything properly, I always had to look things up for myself. No one told me how it might affect me or what problems it could cause for me in the long term, and that was something which really worried me, especially when I was first told.

52. As I mentioned earlier in my statement, I wasn't given any guidance on how to handle my infection with HBV or how I should adjust my lifestyle. My son was still living with me at this point and so it was very dangerous to his health to not provide either one of us with guidance, as I could have accidentally passed the infection onto him. It was very irresponsible of the doctors to not give us any information.

53. I was offered counselling by Liz Farrington while I was on Tenofovir, she referred me to a local doctor. I wasn't interested in it. I was bringing myself out of it all, the way I always did. I did go to see the doctor she sent me to though, even though I think she only sent me there so that they could put me on the medication. The doctor wasn't very helpful and she only gave me a leaflet so I just carried on in the way I always had.

54. It took over twenty years for someone to tell me how I got the HBV infection and it took the same amount of time for someone to treat me for it. I shouldn't have to live with this infection, I shouldn't have to wait until it flares up again to have access to treatment, I should have started treatment the day I was diagnosed. I don't know how it will affect me in the future as I get older, especially as my body is biologically ten years older than my actual age. **WITN3982008.**

55. It was clear that hepatitis was a concern for the doctors who were treating me for leukaemia otherwise they wouldn't have given me the pill to protect me against it. I don't understand how I managed to get it even with the pill.

56. I was never refused any dental treatment, any work that I needed done has always gone ahead. I told my dentist about my HBV infection but nothing changed, I never had to be seen late in the day or noticed any difference in their behaviour towards me.

Section 7. Financial Assistance

57. I have received no compensation and I have received no money at any point for any of my illnesses. Dr Parker referred me at some point to a man who helps people to get compensation for leukaemia, but no one ever mentioned compensation for my infection with HBV.

58. I was never told by anyone about the possibility of financial support, nothing was ever mentioned. No one offered me any financial help and so I have never made an application to any of the schemes.

59. I have now been told by one of the Inquiry's investigators about these schemes offering compensation and assistance for those with HIV and Hepatitis C, and what is required for the application.

60. I contacted the EIBSS after speaking to one of the Inquiry's investigators to establish whether I would qualify? They told me that as I was only infected with HBV I am not entitled to any compensation. The man I spoke with was very abrupt and was quite rude over the phone.

61. I find this decision very disappointing as I have lived with this infection for over twenty years and it has impacted my life in almost every way.

62. I really believe that the EIBSS should expand their remit to include people infected with HBV as well. I have suffered as a result of receiving infected blood and that needs to be recognised by organisations like the EIBSS. It has affected my long term health.

63. Money would not compensate for my infection with HBV but it would ease some of the struggles I face and give me the opportunity to live a

slightly easier life. Also, what about all the other people who have been infected with HBV, are they going to be just forgotten about?

Section 8. Other Issues

64. After everything I have been through, I believe that I do deserve something like compensation and I believe that anyone else who has gone through all of this deserves it as well. I hope that the Inquiry is able to achieve compensation for HBV sufferers like myself, as well those who contracted other infections from contaminated blood.

65. There was never a great deal said about this when I was 62, no one has ever been interested in talking about it until now. I am glad that the Inquiry is listening to people like me and what we have been through, and I am grateful to the Inquiry for doing so.

Statement of Truth

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

Signed **GRO-C**

Dated 18th March 2020