Witness Name: Marlene Elizabeth Bonser
Statement No.: WITN0029001
Exhibits:
Dated: 17th January 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MARLENE ELIZABETH BONSER

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

I, MARLENE ELIZABETH BONSER, will say as follows: -

Section 1. Introduction

1. My name is name is MARLENE ELIZABETH BONSER. My date of birth is GRO-C 1945 and my address is known to the Inquiry. I am married to my husband, Ron. We have three children together. I intend to speak about my infection of Hepatitis C and subsequent cirrhosis of the liver as a result of a blood transfusion.

1.1 In particular, I will go into detail as much as I am able to recall, about the nature of my illness, how the illness affected both myself and my family, the treatment received and the impact it has had our lives.

Section 2. How I was Infected

2. I was diagnosed with Acute Myeloid Leukaemia (AML) in 1979-80. I needed numerous blood transfusions at East Birmingham Hospital, now the Birmingham Heartlands Hospital, due to the Leukaemia and the blood loss. I was anaemic and I bruised easily.

2.1. I do not recall whether I had the opportunity to give consent for the transfusions at the time. At this time, I remember that they hadn't treated anyone with AML at East Birmingham Hospital. I was 33 at the time. I became very ill very quickly and needed numerous transfusions, I do not know how many. I had no issues with the hospital and the way they treated me. If they hadn't have done what they did, I would not have survived. I was in hospital for about six months and ultimately went into remission. I have had no return of the AML to date and so to that degree the treatment had been successful. I subsequently returned to work in 1985.

Diagnosis of Hepatitis C

3. I was employed at Severn Trent Water working in administration. I cannot recall the exact time but at some point between 1992 and 1994, I received a letter from East Birmingham Hospital with an appointment for a blood test, explaining that the test was because I had received blood transfusions in 1979/1980. I went to the hospital and saw Dr Phillips, he told me that with everything I had told him about myself at the time, I seemed fine.

3.1. About a week later Dr GRO-D rang me and asked me to go back to the hospital. When I questioned why, I was told over the phone that my test results had come back positive and I needed to have another appointment to see him to discuss this issue. I remember calling Ron and my daughter Sarah, I just wanted family around me at the time. A few days later, I returned to the hospital to discuss the diagnosis with Dr GRO-D He told me that it was Hepatitis C and that it was not good and there was no cure for it. He was very frank, he told me that it would kill me. He did say that if my liver failed that I could maybe get a transplant but getting an available match was not as easy as it sounded.

3.2 At this point I received no real explanation about Hepatitis C, I was not given any leaflets or literature. I was not offered counselling.

3.3 I was then transferred to Queen Elizabeth Hospital under Dr Mutimer. He was an Australian and very good, he explained more about the condition but did say that if I got another five years (of life), that would be good.

3.4 This was very disturbing. At this time two of my children were still at home, one was away, in the army.

3.5 I was not informed where the blood had come from, just that contamination of blood supplies had become a problem.

3.6 Ron had been a blood donor for years and had to be removed from the register because of my condition despite having nothing wrong with him. The worst part was that he had been told of this in a public area, for all to hear.

3.7 I never really felt ill when I was diagnosed, it came as a shock. I was tired but I put it down to my age, running a home and working full-time. I never put it down to a serious illness at all.

3.8 When I was diagnosed I had to go for a scan and a liver biopsy and I was told that I had cirrhosis of the liver too and that this was effect of the Hepatitis C. Because there was no treatment, the cirrhosis was just getting worse. I was informed they were checking my liver because it could also become cancerous. My mind used to go into an overdrive because I had had leukaemia and it looked like I had beaten it (in remission since 1980) but then the treatment had caused me to get

Hepatitis C, which could give me another cancer and so it goes on and on.

3.9 I was really angry at first but I talked myself out of it because there's no point in being angry as I've had all these years which I wouldn't have had, had I not had the blood. It's like a catch-twenty-two in that way. If I hadn't had the blood, I would be dead but the blood I was given was going to eventually kill me.

3.10 I was informed by Dr Mutimer, that I would have to make regular visits once a month for consultations, blood tests and scans of my liver, to monitor how my liver was behaving. My own GP didn't know anything about Hepatitis C so she used to say that she couldn't treat me because she didn't know anything about it. She did say she had another patient who had Hepatitis but I was different because I had Hepatitis C and the other patient didn't. It was difficult, I couldn't just go to the hospital every time there was an issue but my GP was no help at all.

3.11 In all I have been involved in two trials, whereby each time I underwent a course of treatment. Both had a severe effect on me and made me very ill. I explain more below under 'impact'.

Section 3. Other Infections

4. I have not received any infection or infections other than Hepatitis C (HCV). Although obviously, the cirrhosis came about due to the Hepatitis C.

Section 4. Consent

5. I do not believe that I was treated or tested without my consent.

Section 5. Impact

Physical and Psychological Impact of Infection

6. As mentioned earlier within this statement my infection of Hepatitis C resulted in cirrhosis of the liver.

6.1 Around 1996, about 3-4 years after I had been diagnosed, I started a medical trial under Dr Mutimer. This involved self-administering Interferon and Ribavirin with a syringe needle at home. There had been some success with this trial previously and I was informed that I could carry on going to work but I'd got flu-like symptoms. I found self-administering these drugs very difficult.

6.2 This trial hit me really hard and I ended up having severe depression, a side-effect of the drugs that I was not made aware of. I had experienced depression after having my children but nothing like this: just to get out of bed it was wicked, it was just all-enveloping. I tried to go to work and I would just be crying at work. A colleague would ask me why I was crying and I just didn't know, and this was at a time where they weren't as sympathetic as they would be now, I was told if you're going to cry like this you may as well go home and not come back. I was supposed to just have flu-like symptoms but I felt like I was dying.

6.3 I was on the trial for about four months and I went to see Dr Mutimer who stated that I was obviously a person who was susceptible to depression and that the trial did not seem to be working for me. I was taken off the treatment and as soon as I was taken off, my health started to improve and I was able to return to work.

6.4 I was transferred over to Dr Freshwater's clinic and in 2003 he stated he thought that I should go onto this new treatment. When I was diagnosed I was told there were three strains of Hepatitis C, one, two or three. One, which is what I had, was the worst. If I had had two or three I could have had a six-month trial, but with this new treatment I had to do the trial for twelve-months. Dr Freshwater told me that I needed to go on this treatment because my liver needed a rest, that it was currently inflamed and the twelve months would give it relief.

6.5 I declined at first because the previous treatment had made me so ill and there were no guarantees of success; the depression I had suffered with the previous trial had made me petrified to go on the other treatment, I couldn't go through that again. Therefore, I stated that I would not go on that treatment unless I was very ill. My son was about to get married and I didn't want to be ill for that.

6.6 However, after my son's wedding, I did start this new treatment and it was terrible. I would administer it myself at home once a week: this time it wasn't a normal syringe, it was similar to an EpiPen and I would get the pen and I would hold it quite firm and push my body into it, I couldn't do it any other way. The pen was easier than the needle I used in the first trial because the two ingredient drugs were mixed together for me, so the amounts were never wrong. But it was just hard, hard on the stomach. We had to pay for these prescriptions too, which angered me; it was something they (the NHS) knew that they'd given to me and knowing that, I still had to pay for prescriptions.

6.7 As a result of this second trial I was virtually bed-ridden for twelve months. I couldn't work, and it was just as well that my husband, Ron, was retired because we couldn't have coped otherwise. We had no social life, couldn't do anything socially for twelve months. I used to shower, try and get dressed and make my bed and that was it, I was exhausted. If I got dressed it would give me the feeling of being normal, not in my nightie and ill. But having a husband like I had, he was very good and he looked after me very well but he never let me wallow in self-pity, he made me look forward.

6.8 As I had severe depression with the previous trial, I was asked if I needed a clinical nurse through the trial. I agreed because I felt that I needed someone who knew what I was going to go through to help me, but every time I phoned this guy up he was unavailable. I spoke to one of the specialist nurses and she asked me if I wanted to be put in touch with a young lady who was in a similar position as I was. She had been through the six-month treatment. She was always on the other end of the phone for me and would come over. It was a great help at the time. Other than that, I received no counselling.

6.9 We didn't find out the results of the trial until six months after the trial had ended. We found out the Hepatitis C was cleared, which was good but, unfortunately, I still had cirrhosis of the liver which I had been told could lead to cancer.

6.10 Now I have to go to the hospital twice a year to monitor my liver. They scan and take my blood and we get a result on the day. There has been a little bit of recovery. They had a new fibreoptic scanner at the hospital and Dr Mutimer scanned my liver and he informed me that it looks like there's been a little bit of an improvement, although it may have been that the new scanner was more sensitive and was able to give a more accurate reading than the ones used in 'Imaging'. The main thing was that there had been no deterioration.

6.11 My health now is up and down; I'm always tired and cold. I'm up about 8-8.30am and I am in bed by 10pm every night, always tired and ready to go to sleep. Also, it's recommended I don't have any medication other than paracetamol because of the effect on the liver. This has affected me most because I have arthritis in my pelvis. I do have exercises to do but the pain can get really bad. I can take paracetamol but nothing stronger in case my body gets used to it, meaning that if the arthritis got worse I would need something stronger in the future, which would not be good for my liver.

6.12 The biggest problem is you never know if it is cancerous. It is like the sword of Damocles. That's the biggest impact, that we don't know what the future holds: whether it's a month, a year. Seeing my great-granddaughter grow up, she's only seven, it's that sort of thing.

Financial Impacts

7. I worked for GRO-D at the time on the banking side, in administration. It was a physically, easy job but it was the concentration. I had a lot of time off work and eventually I was told by HR that I had to go. I had done 13 years and was halfway to qualifying for my full pension.

7.1 The biggest impact was that we (Ron and myself) had to go to the hospital and take time off work once a month. I was always classed as sick and I was penalised at work for this. They would have attendance-based bonuses, which I wasn't entitled to even though my attendance was 100% otherwise. Human resources and two other people at work knew. I would have appraisals and my line manager would tell me that my work was good, my attendance other than hospital was good, my training (of others) was excellent. They were happy with my work but they told me they couldn't give me what other people had because of my attendance record. The only rise I would get was the annual rise, in line with the rise of living costs.

7.2 During my second trial, I had twelve months off. I had got up to go to work one morning and I just couldn't get out the door. I tried to go back after the twelve-month period on a part-time basis and people at work weren't happy about it because they thought I was getting preferential treatment.

7.3 Consequently, I retired early when they said they couldn't accommodate me anymore at GRO-D This was in 1999 when I was fifty-four. I went to see an independent doctor who told me to go home and enjoy retirement and the time I had left because there was no treatment for me and it would eventually kill me, so he wasn't going to tell me to go back to work. I felt a lot better with this decision because I felt I could take up the throws of life again. However, as I previously mentioned, I had worked thirteen years with GRO-D and I'd have had to have worked at least twenty-six years to get the full pension. We still receive the pension now, but it wasn't even half the salary because I had to retire early. We lost quite a lot of money as a result of my enforced retirement.

Social Impacts

8. I didn't tell anybody I had Hepatitis C because of the stigma. I felt really dirty. I didn't know where it came from: drug addicts, prostitutes. I'm a very clean person but it made me feel really, really dirty... contaminated. I felt that if others knew they would not want to be around me. My friends know, now that everything is clear, but they never knew at the time I had it.

8.1 It impacted our social life. We lost friends from it, both from the stigma and not being able to go out when I was really ill. It also knocked my confidence back and I've never got it back to where it was.

8.2 I used to like a drink on social occasions but I was unable to take alcohol due to the state of my liver. I now might have a very occasional glass of wine, particularly if it's a special occasion but I have to be careful.

8.3 When I was going through my treatment my next-door neighbour was a nurse at Heartlands and she knew I was ill. She told me to always tell the doctors what was wrong with me and how I got it otherwise I'd be treated appallingly. I still do this now: I always state that it isn't drug or alcohol related, that it was because of contaminated blood.

8.4 When I had Hepatitis C going to the dentist was a nightmare. They always made sure I was the last patient and they made it known why. The hospital was the same. I was told that I had to be the last patient because I was a risk. They didn't tell me on my own and privately in an office, they told me publicly.

Impact on Private and Family Life

9. My children were roughly twenty-six, twenty-two and twenty when I was first diagnosed with Hepatitis C. My oldest wasn't living at home, but the other two were. In the difficult periods, through the clinical trials, I couldn't do anything for anyone, my husband did everything. I was just too ill.

9.1 I mainly missed out with my grandchildren when they were young. It was only in recent years that my grandson, by now grown up, said that he didn't like to come over because he was scared of me – my demeanour and appearance scared him. He said that he hated coming to see me. It is really hurtful to think of that.

9.2 Financially it affected my family because I had to retire from work and I couldn't do things like take the grandchildren on holiday and do what I wanted to do.

9.3 My daughter and son were really upset with the way things were, but for the second treatment trial, they did as much as they could. My daughter is very angry about all of this now. She felt I was going to die, and she had sleepless nights and it used to make her feel ill.

9.4 It's also greatly affected my husband, Ron, who has had to look after me throughout this.

Section 6. Treatment/Care/Support

10. I couldn't condemn the treatment we had from the hospital because they were very good.

10.1 I have not ever received counselling or psychological support in consequence of being infected.

Section 7. Financial Assistance

11. I received compensation from the Skipton Fund in the late 1990s. The nurse in the clinic told me about it because they weren't issuing information: you had to ask for it because if you didn't ask, they didn't have to pay. I subsequently received £20,000.

11.1 In 2011, I got a phone call from the Skipton Fund. The man said that they "had some good news for me, we're going to give you some money for the inconvenience of having infected blood". After the first payment I thought we had waived our rights. I didn't think, the way the government was, that I'd get any more money at all. It was a big bonus for me. I got another £20,000 and for the complication of the cirrhosis, I received £25,000.

11.2 I also get a monthly pension. It was originally £12,000 a year but is now around £15,000.

11.3 The money makes me feel guilty because I have come through it and generally feel fine now.

Section 8. Other Issues

12. I went to a solicitor, GRO-D just after my diagnosis regarding action against the NHS for my infection. He asked me how much we earned, whether we owned our own home and how many children we had. He advised us that on the information I had given, if we went forward against the NHS we would end up bankrupt with no home and therefore to forget about it and go home. I have not sought legal advice since.

13. Finally, I would like to say that I am angry and disappointed that there has been a cover up and that it has taken all these years for something

to be done about it. It is unbelievable that there are people out there that have such disregard for people's lives and their families. This is a devastating thing to have to happen to you and your life. At least with the leukaemia, which was nobody's fault, I knew I was reasonably clear after five years of being told so. However, with the cirrhosis, caused by the Hepatitis C which was caused by the contaminated blood, I am never free of the thought that this could kill me. There will never be closure for me or my family.

Statement of Truth

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

Signed GRO-C

Dated 14/01/2019