

Witness Name: Jacqueline Bailey

Statement No.: WITN0750001

Exhibits: **WITN0750002**

Dated: 22-05-2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JACQUELINE BAILEY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 01 March 2019.

I, Jacqueline Bailey, will say as follows: -

Section 1. Introduction

1. My name is Jacqueline Bailey. My date of birth is GRO-C 1955 and my address is known to the Inquiry. I am separated from my husband and I work part time as a partner in my own cleaning business. 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.
2. I confirm I am not legally represented and I am not seeking anonymity.

Section 2. How Infected

3. I have no tattoos and I have never used drugs. As far as I am aware, I only had one blood transfusion, during the birth of my daughter in 1984. My consultant has confirmed this as the likely source of my Hepatitis C infection.
4. My daughter was born on [GRO-C] 1984 in the British Army Military Hospital in Hanover. My husband served as a Lance Corporal in the army. I already had a son who had been born naturally. When I had my daughter, I was overdue and required a caesarean.
5. I do not remember much, but I vaguely remember being advised afterwards that I had lost a lot of blood. However, as far as I am aware, I was not advised that I had received a transfusion nor of any associated risks of infection. From my records, which I eventually managed to obtain, I know that I had two units of blood (Exhibit W0750002).
6. In approximately 2011, I noticed I was increasingly incredibly fatigued. I visited multiple doctors, but I did not find out what was wrong. However, I knew my body and I knew something was wrong.
7. Eventually, I saw Dr Gregory, I believe his name was, at the [GRO-C] Practice who suspected I had hepatitis and performed a blood test. My doctor telephoned at the end of that week and advised me that I did have Hepatitis. I do not think my doctor should have told me the news of my infection over the telephone, but rather I wish he had called me to make an appointment to see him in person. That way, whilst I would have still suspected it was bad news, I would not have been left panicking by myself. I was driving myself mad pacing around the room whilst on the telephone with him. I feel it would have been better had this been said to me face to face. I was alone when I

was told because my husband had just come off a night shift so he was sleeping and I didn't want to wake him. The news knocked me for six.

8. I did not know how I could have got Hepatitis. I associated it with prostitution and drug use and those sorts of things were taboo when I was brought up. I asked the doctor how I could have got it and he suggested the source of the infection could have been my husband's first lover. I was my husband's first lover and I told my doctor not to continue that line of reasoning. I didn't want to hear it and I could have slapped him and I admit I did tell him so at the time. My doctor apologised. I think he was trying to help me understand how I became infected and, whilst I was listening, I did not feel I was fully there; it was as if this was happening to someone else. I was in panic mode. My doctor also suggested I could have become infected via my mother and, whilst I thought it unlikely, I did not know and supposed it could have been feasible.
9. My doctor did not give me any advice about managing the infection or the associated risk of infecting others. I was so chuffed to have found a doctor who knew what was wrong with me, but I do feel he should have provided more information to me at that stage so that I had the information sooner. I feel I should have been told more from the word go.
10. My doctor told me to come to the GP surgery and get a form. He told me I needed to get a blood test that day at the hospital to find out the type of Hepatitis. I do not know how I managed to do this. He later referred me to a consultant at the Royal Derby Infirmary. I did not have to wait long. The consultant confirmed that I had Hepatitis C. He asked me if I had received any blood transfusions or had any operations. I told him I had undergone a caesarean with my daughter. The consultant made the connection between the infection and the 2-units of blood I received.

11. I did not see the consultant again, but he set me up with a team of two fantastic nurses. I cannot remember their names, but they were brilliant and took care of me. They would even stay late to see me so I could continue working. They explained the risks and the management of the illness to me.

Section 3. Other Infections

12. As far as I am aware, I was only infected with Hepatitis C.

Section 4. Consent

13. As far as I am aware, I have always been treated with my full knowledge, understanding and consent. I was asked and consented to the nurses taking some extra blood from me for research purposes. I believed this was the right thing to do in order to prevent this happening to anyone else. I felt that, if I could help, I should.

Section 5. Impact

14. Physically, the Hepatitis C infection was very draining on me. I did not feel like my normal self. I experienced chronic fatigue and this continues to this day. I cannot drive long distances. My tiredness has got worse recently and so I am returning to my GP in fear that the Hepatitis C has come back. Some days, I could not get out of bed and I recall spending whole weekends bedridden.
15. I was diagnosed with rheumatoid arthritis in my wrists and I now have it in my knees. I am unsure if this is related to the Hepatitis C infection, caused by my work or caused by the fact I had rheumatic fever when I was young.

16. I am unable to donate blood, though I would dearly love to. This is, in part, due to the Hepatitis C now, but I was unable to even when I enquired previously due to the fact I had rheumatic fever when I was young.
17. As the Hepatitis C went undiagnosed for nearly thirty years, my liver was damaged. I have been told that if it becomes cirrhotic then there is nothing much that can be done, which does scare me. It will only be controllable, not curable. I have been told the Hepatitis C may come back by my consultant, but my GP thinks this is not possible and so I am left unsure.
18. Mentally, the Hepatitis C infection has impacted me severely. Looking back, I was paranoid about infecting someone. I remember cutting my finger and someone offering to put a plaster on it for me, but I could not let them do so for fear of infecting them. I had to do it myself. I still am paranoid about this sometimes. I have often wracked my brain worrying about times I could have infected others.
19. My husband would question whether I was playing up the impact the Hepatitis C had on me and this did impact our marriage. I became very low and I was prescribed antidepressants. I am still on these, even now, though I am slowly weaning myself off them because I do not like taking medications. The Hepatitis C infection, and all that occurred as a result, caused my depression. At the time, I could not cope. I had taken medications previously for feeling low, but never for an extended period. I have been on antidepressants for five years now.
20. The worries and fears never leave your head. It is hard to let it go. No one knows what it is like to be infected with Hepatitis C unless they have gone through it themselves. At the time I was diagnosed, I felt dirty because I associated the infection with prostitution and drug

use. I would not wish Hepatitis C or the treatment to clear it on my worst enemy.

21. Fortunately, the infection has not impacted on my other medical care. I did have to inform my dentist and such that I was infected, but their attitude towards me did not change. When I had operations subsequently, I was fortunately kept on a ward with other people. I never experienced isolation wards and I was never refused treatment because of my infection.
22. Socially, I initially felt unable to tell others about my infection. I had to limit my drinking when out with friends and when they would ask about it, I would have to cover everything up. I do talk about my infection now, however. I remember talking to someone else who had been infected. She was told that she could not be cured and that did make me worry more. However, it was good to talk to her because she knew how it felt and I felt unable to talk to anyone else who hadn't experienced the disease. I was ashamed.
23. I remember that a friend's father died from cirrhosis caused by infected blood. I recommended the financial support that I had become aware of, as I felt I could help my friend and his family as barely anyone knew of the ability to claim that financial support. In the end, I believe his family did not claim the financial support. I only felt comfortable talking about it with him because his father had died from the same infection that I had.
24. I have been fortunate in that I have not experienced the stigma associated with the infection, though I did initially associate the infection with drug use and prostitution myself. To be honest, I told nobody outside my family that I had Hepatitis C.
25. The Hepatitis C infection did impact my work to some extent. I continued working throughout the diagnosis and treatment because I

am the kind of person who needs to have something to focus on to get me through. However, I could only work a couple of days a week due to the fatigue and, particularly during treatment, the medications. My nurses could not believe that I kept working. It was not easy to keep working, it was very hard in fact, but I did not want to let my business partner down. Although, I do think I was terrible to be around and work with during treatment, so I think perhaps my business partner wanted me to have more time off!

26. Financially, I have been impacted because, although I had a house, I did not have much equity in it. When my husband and separated, this left me struggling on my own. I have incurred expenses going to and from the hospital and I have lost income by being unable to work as much as I would have liked.

27. The impact on my family has been severe. I do not think my husband coped well with knowing that I was infected. The physical and mental impact on me had a knock-on effect on him. It impacted our sex life, as I did not want to infect him. Even now I would not be with anyone for fear of somehow passing it on. During treatment, I was very snappy and unpleasant and this put a strain on the marriage. GRO-D

GRO-D I did not confide in anyone as to how ill I actually was. My husband could not understand what I was going through. GRO-C

GRO-C We are still good friends. I do think that, were it not for the Hepatitis C, my husband and I would still be together; we separated within two years of my diagnosis.

28. It was only after a chat with my sister that I confided in my family the extent of my illness and its impact on me. My sister said she had not realised quite how bad I was and that was part of the problem. From then on, I did tell my family how ill I was and so I have had more support. It was my own fault that they did not realise that I needed support from the start because I would not tell them.

29. My children were in their late 20s / early 30s by the time I was diagnosed. I did worry about cuts and scrapes, retrospectively wondering if I might have infected them. My daughter GRO-C
GRO-C My son GRO-C
does not think it could have affected him. He does not talk about the impact on him.
30. My daughter worries about me a lot. She visits more frequently than she ever did before my diagnosis. I am now fully open with my children, though I was not always. I remember she would call and ask how I was and I would reply and say I was fine and she would tell me that she knew I was not fine. She especially worries about me now that I live on my own. I do go home to Ireland more often now to visit family, though it is sometimes a struggle because of the fatigue and financial burden.

Section 6. Treatment/Care/Support

31. I do not remember the name of the treatment I was given, though I believe it might have been Interferon and Ribavirin. What I do know, however, was that it made me feel awful. I injected myself once a week and I had to take tablets every day.
32. I would have the injection on a Tuesday and by Friday I would slump. I would get flu-like symptoms and I would be in bed for the whole weekend. My husband did not understand what I was going through and would often leave me alone. Often I was in bed, alone, unable to get up all weekend. I was unable to work Monday and so I had to change my work schedule. My business partner was very patient and understanding because she knew I was not a well woman. She deserves a medal for her patience.

33. During the treatment, my whole personality changed. After the treatment was finished, my business partner told me that I had been a really nasty person on the medication. She said I was snappy and aggressive. I knew that I was, though I didn't notice it initially. I found it hard as I tried to stop it but I couldn't. Once I completed the treatment, my business partner, as well as my family, have commented how nice it is to have me back again. It is like I was a completely different person. The treatment lasted around nine months as far as I recall.
34. I experienced being too hot at night and night sweats. I would have to sit in the bathroom, where it was cooler, which disturbed my husband and put a strain on our relationship. I could not sleep beside him. At one time, I recall having a rash over my entire body for approximately two months. I would sit in the bathroom at night and cry. The itching was unbearable and there was nothing I could do to stop it. The nurses were brilliant and did say I could call whenever. After a few nights of being unable to sleep, I did call them and they told me to go to the hospital so that they could see what they could do. They gave me something that did soothe it a bit, but there wasn't much more they could do.
35. I could no longer dye my hair, as my scalp was too sensitive. I did not lose my hair, though it may have thinned slightly. I was still incredibly fatigued; I would get home from work and collapse into bed. I would definitely not want to go through that treatment again.
36. I was not told that I had cleared the virus, but that all the tests had come back normal. I was told it was still possible to relapse. I worry about this and the liver damage that has occurred. Even after the treatment, I cannot get complete peace of mind, though I am better than I was.

37. I have not had follow up blood tests or care. I have, on my own initiative, asked for blood tests and these have always come back normal. I am going to ask my GP to be checked again soon as I am experiencing chronic fatigue again.
38. I never experienced any obstacles in obtaining treatment for my Hepatitis C.
39. I was never offered any psychological support or counselling. I do not know if I would have taken the support, had it been offered. I believe I might have accepted help later on, though, once I realised the extent of the mental impact of the Hepatitis C and the treatment.

Section 7. Financial Assistance

40. The two nurses that looked after me told me about the Skipton fund. They said I might not be eligible, but I gave it a go. I found the application process went quite smoothly. The only hiccup I encountered was in obtaining my medical records from the army. I do not recall any preconditions to my obtaining financial support. I never applied to any other financial support, as I only knew what the nurses had told me.
41. I received £20,000 as a stage one payment from Skipton. I now receive regular payments from EIBSS. Initially, this was £300 and something a month. I was sent forms about a top up, but I did not really read them until I got a reminder. My daughter encouraged me to take the financial help offered as I was struggling. I completed the forms and now receive £500 and something a month from EIBSS.

Section 8. Other Issues

42. I feel that none of this should have happened and I hope it will never happen again. I think it is awful when I look back on it now. I know I

am a lucky one and that some people didn't pull through. It is awful knowing that people have died.

43. I have signed a consent form dated 17 May 2019, which has been explained to me and I am prepared for this to be used once my statement is agreed and signed.

Statement of Truth

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

Signed GRO-C _____

Dated 22-05-2019

