28 Oct. 2019

Witness Name: Karen Bolton
Statement No.: WITN0463001
Exhibits: Nil
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF KAREN BOLTON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 17 April 2019.

I, Karen Bolton, will say as follows: -

Section 1. Introduction

1. My name is Karen Bolton. My date of birth is GRO-C 1964 and my address is known to the Inquiry. I work for the Bolton Council. I intend to speak about my experience of Hepatitis C. In particular, the nature of my illness, how the illness affected me and the people in my life, the treatment I received and the impact it had on me.

Section 2. How Infected

2. I believe I was infected with Hepatitis C through a blood transfusion in October 1989 at the Royal Bolton Hospital. I received the transfusion shortly after giving birth to my daughter, Sarah.

3. During labour, I lost a lot of blood. I was therefore transfused with two and a half pints of blood.

4. I did not find out that I was infected with Hepatitis C until 1998. I was admitted to hospital with excruciating stomach pain following a trip to Marbella. I thought that either I had pulled a stomach muscle while playing in the pool with the kids, or I may have contracted food poisoning.

5. In hospital, I was given Morphine for the pain. I was told that it was likely that I had food poisoning caused by Campylobacter from chicken that I had eaten in Marbella. Still, the doctors were unsure and so they ran a full set of blood tests.

6. When the blood tests results came back, I was told that they had picked up a problem with my liver. I was discharged and told to come back to see the liver specialist.

7. When I went back to the Royal Bolton Hospital, the specialist admitted me again. He told me that I may have Crohn's Disease or Cancer or Irritable Bowel Syndrome but that he wanted to do a liver biopsy.

8. I was told after the biopsy that I had Hepatitis C. I remember that the doctors asked me all of the usual questions about being a drug user, having tattoos or having transfusions. I told them that I had not had any tattoos, was not a drug user and had not had any transfusions aside from the one in 1989.

9. I had never heard of Hepatitis C. The doctors at the Royal Bolton Hospital also seemed to know very little about it. It was very distressing to be provided with so little information. They had no idea how to treat Hepatitis C.

10. I was incredibly stressed and had no idea of what was going to happen to me. I felt like I was being provided with inadequately little information.

11. The doctors at the Royal Bolton Hospital told me that the Royal Manchester Hospital would be better able to treat me as there was a

level of expertise about Hepatitis C there. I was therefore transferred to the Royal Manchester Hospital on Oxford Road.

12. Dr Lipscomb at the Royal Bolton Hospital was very good. He told me that he wanted to keep me registered at his hospital and set up a Hepatitis C clinic in Bolton, but that did not happen.

13. After a couple of months, I finally got an appointment at the Royal Manchester Hospital. Only then did I find out about the treatment options for Hepatitis C.

Section 3. Other Infections

14. I do not believe that I have received any infection or infections other than Hepatitis C through infected blood or blood products.

15. I know that I contracted Hepatitis B when I was sixteen but I cleared it shortly afterwards. The doctors think that I got it from a sharing a cup with a friend.

Section 4. Consent

16. I do not believe that I have been treated or tested without my knowledge or consent, or for the purposes of research.

Section 5. Impact

17. Before I was diagnosed with Hepatitis C, I noticed that I was much more fatigued than I had ever been before. When I was at work, I would feel compelled to have an afternoon nap. I wanted to curl up under my desk and sleep because I was so drained.

18. It was only when I began treatment, however, that the real impact on my life began.

19. As I mentioned, I only found out about treatment options after I was transferred to the Royal Manchester Hospital. I waited months for an appointment there and then months to start the treatment. The gap between being told I had Hepatitis C and beginning treatment was five months. This was an unacceptably long time.

20. In 2001, I began my Ribavirin and Pegylated Interferon treatment. I think I was part of the third group ever to try this combination therapy. I was admitted to hospital at the Royal Manchester for four or five days. I was in a group of people on the same treatment. We were each on a kind of camp bed rather than a hospital bed. We were taught how to administer the injections directly into our stomachs and how to take the tablets.

21. After those five days, I was discharged. For the next ten to twelve months, I administered my own treatment and was required to go to the hospital every two weeks for a blood test. The gaps between the blood tests then increased to three weeks.

22. The side effects of the treatment were horrendous. The doctors told us that we would experience flu-like symptoms. The symptoms hit me hard. About an hour after each injection, I would feel fluey, feverish and I would start shivering.

23. During the course of the treatment, I lost a lot of hair and a lot of weight. I had a permanent metal taste in my mouth and couldn't bring myself to eat much. I went down from nine stone to a size six. A woman at work brought me hand-me-downs from her eleven-year-old daughter.

24. The mental effects of the treatment were absolutely awful. I became very forgetful. It felt like my memory was gone. I wrote notes and more notes for myself. It was scary how little I would remember. For example, I left the cooker on by mistake. I was very lucky that I didn't burn the whole house down. I also became erratic. I'd lose my temper much more quickly than is normal for me.

25. Perhaps the anxiety and depression were the worst of the side effects. It felt like being in a black hole. I had never felt like that and I never want to feel that way again.

26. I remember sitting in the shower and crying inconsolably. Sometimes I would sit in the car park and cry because I did not want to go home.

27. When I was on the treatment, I would phone Samaritans two or three times a month in floods of tears. I would get so overwrought. Often it was because I was so desperate to sleep because I was exhausted, but my brain would not stop whirring. I would drink in an attempt to fall asleep. I would get so frustrated.

28. One night, about half way through the treatment, my partner found me passed out downstairs. I hadn't been able to sleep so I took sleeping tablets. They were not working quick enough, so I took more than I should have. I had also been drinking. I was in a very dark place at that time which now I know was caused by the side effects of the medication I was on at the time.

29. I was admitted to the hospital. The next afternoon when I came to, I was asked whether I tried to commit suicide. I didn't. I just wanted to go to sleep.

30. It doesn't surprise me that many people in my position stopped the treatment. Twelve months is a very long time to feel that way. My Mom, kids and my dog got me through the treatment. My mother would make sure to visit me almost every day to goad me on. I was lucky to have had the support that I did.

31. That said, it was difficult for them. My son was terrified that I would die. He was very distressed at the time. I would lose my temper and end up having a screaming match with them. My mother was particularly good at reminding my sister and my Dad that it wasn't me that was talking.

She understood that I was entirely overwhelmed and almost taken over by the effects of the treatment.

32. I think it's fair to say that the mental effects of the treatment broke up my relationship with my partner. My mood swings were too much for him to bear. He would listen to me but I am not sure that he really understood what I was going through. I don't think he was looking, but he found somebody else and we split up. He could not cope with my illness.

33. I was very lucky that Bolton Council was so supportive throughout my illness. While I was having treatment, I was off on full pay. I did not feel rushed to come back to work.

34. My income was, however, diminished by the fact that I could not work my second job at a pub. By then, I had worked at the pub in the evenings for twenty-two years. I used to work for about fifteen hours a week which helped to pay the bills. I could not keep up the brave face and act jolly behind the bar when I felt so diminished.

35. Financially, things became a bit of a struggle. After my partner left me, I struggled to pay the bills and ended up losing my house.

36. After I finished the treatment, things improved. I was off work for five months on full pay after the treatment ended. When I finally went back, I would sometimes burst into tears in the middle of meetings. It was very embarrassing.

37. Again, the Council was very understanding. If I woke up and didn't feel able to go to work, I would stay home and it was never a problem.

38. My colleagues were also very supportive. I was very open with them about my diagnosis. At work, I told people I had Hep C. There were some people of the old school of thought that subtly avoided me a bit. For the most part, though, my colleagues would banter with me. I used to jokingly say to them "don't sip out of my cup – you might catch it!".

39. About two years after I started treatment, I was told by the Royal Manchester Hospital that I was clear of Hepatitis C. This was in 2003. When I told the doctors that I was still struggling with the mental effects of the treatment, I was told to take this up with my GP and essentially to sort it out on my own.

40. I am grateful to my GP, Dr Patel, that he helped me to manage the mental effects of the treatment. Together with Dr Patel, I figured out a combination of medicine that stabilised me.

41. Despite the passing of sixteen years, I would not say that the mental effects of the treatment have entirely gone away. I am still taking Zopiclone (one or two a night to help me sleep), Propranol (one in the morning and one at night) to "level the playing field". Propranol is a beta-blocker. Also still taking Citalopram 30mg a day which is an anti-depressant.

42. I still have some anxiety and depression though I am able to manage it. Since the days of the treatment, I been able to stop myself going over the precipice of the black hole. I still feel very fatigued sometimes, and I still have Irritable Bowel Syndrome.

43. Before the treatment, I was a very relaxed person. I was not anxious and did not get overwhelmed. Now, I have to manage my anxiety. For example, I know that I battle with crowds and with people being in my space. To combat this, I go food shopping quickly and methodically at shops that I know. Either I go early before work or late in the evenings near closing time. That way, I know that the shop will be fairly empty.

44. Unpredictable, new and busy places continue to make me feel anxious. I far prefer going to restaurants and bars that I know well. If I go to a new place, I ensure that I orientate myself at the beginning of the evening. I will make sure that I know where the doors and toilets are. It is a way to keep my panic under control. I find myself thinking about

what would happen if a fire were to start or if too many people come into the space and I can't breathe.

45. Generally, I am good at managing myself and my anxiety. It does, however, sometimes get the better of me. When I was in Disneyland with Sarah and my grandkids, I had a panic attack in a toy shop. After we went into the shop, a lot of people entered and I felt completely overwhelmed. I couldn't breathe. I had to calm myself down, tell myself to breathe, and try to be rational.

46. Now that my family realise this side of me, they take it on board and watch out for me. They will ensure that the places we go to are not too busy. I realise how much I have changed when I think of things that I used to do, like go to the football matches at Anfield, Liverpool, which I would never contemplate now.

47. I have luckily been spared from the stigma that I know some people face. Maybe this is because I have always chosen to be very open about my infection with Hepatitis C. I spoke to people about what I was going through and how I was feeling. I was lucky to have the support system that I did.

48. The most stigma, perhaps, that I faced was my dentist's discomfort with treating me after I told him about having Hepatitis C. I found a new dentist, however, and have been going to him for years.

Section 6. Treatment/Care/Support

49. As I have mentioned, it took five months before I got the go-ahead for treatment. That was a "bug-bear". As a result, I don't have much faith in the National Health system and their recommendation of treatment.

50. For example, I have been told that Hebravin may be a treatment I should go for to get rid of the Hepatitis C antibodies that I still have in my blood. But I feel that when I ask, the doctors do not clearly set out

what is wrong with me and how the treatment may help. I feel like I have to find out about treatments and then ask about them otherwise I won't be told.

51. I feel that better psychological help should have been provided. I received counselling through work. I have never found it hard to find someone to talk to. What has been hard is to find people to talk to who understood what I was saying and going through. People who would not just listen but understand.

Section 7. Financial Assistance

52. Around 2005 or 2006, I received a £20 000 once-off payment from the Skipton Fund. I was asked to sign the pro-forma waiver of all other claims.

53. I never received an annual or monthly payment from the Skipton Fund. For past 18 months, been getting money from EIBSS. They contacted me in December 2017 and I filled out an application form. I had to get my doctor to sign it. I get a sum of money every quarter. It's just gone up to £4 608 quarterly (as of 26 April). I also get a winter fuel allowance of £531. It works out to £18 432 per annum broken down into 4 payments.

54. I didn't have any difficulties with any of the Funds. In fact, I didn't ever expect any compensation. I wanted and still want to know why it was still going on – why contaminated blood was being given to people for such a long time even after they knew it was tainted well before I had my transfusion.

Section 8. Other Issues

55. I really believe that it is diabolical that the NHS was still giving out infected blood in 1989 when it was known that blood was defective in

1983. I cannot understand why the infected supplies were not pulled straight away.

56. I really hope that those being diagnosed with and treated for Hepatitis C are being given full information in terms of the side effects to be expected and effective counselling. I really resent that that I was not told about any of the treatment's side effects except for cold and flu. Maybe I could then have handled it better and been better prepared. I also would have made a more informed decision about whether or not to proceed with treatment.

GRO-C

Statement of Truth

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

Signed GRO-C

Dated 28 Oct. 2019