Witness Name: Elizabeth Deenagh Foster
Statement No.: WITN3529001
Exhibits: **WITN3529002**
Dated: 13/8/2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF ELIZABETH DEENAGH FOSTER

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

I, Elizabeth Deenagh Foster, will say as follows: -

Section 1. Introduction

1. My name is Elizabeth Deenagh Foster (Deenagh). My date of birth is GRO-C/1946 and my address is known to the Inquiry. I am now retired but worked part-time up until July 2018 in order to supplement my reduced pension. I live with my husband of 21 years. I have two children and seven grandchildren.

2. I will speak about my infection with Hepatitis C as a result of a blood transfusion I received in 1987.

Section 2. How Infected

3. On 15 November 1987 I suffered an ectopic pregnancy and collapsed at home. My GP was called and he sent me straight to the Buchanan Hospital in Hastings where they performed emergency surgery (salpingectomy) to remove the pregnancy. I remember feeling incredibly cold and weak.

4. I was given a blood transfusion on the ward post-op. I have obtained the brief operation record from my archived medical records which mentions nothing of the transfusion. From my own medical notes, it is recorded that I received five units of blood. I produce this document as **WITN3529002.**

5. Almost exactly six weeks later, around 5 January 1988, I was about to get re-married and was preparing the house for a small reception. I found that I was utterly exhausted and just couldn't get the work done. I also had steatorrhea (pale or white faeces caused by the excretion of abnormal quantities of fat).

6. I decided that I should make a rare visit to my GP on 8 January 1988. She took one look at me and said, "You are severely jaundiced, have you not noticed?" I replied that I hadn't noticed because I had not looked in the mirror, but that I really did not have time to be ill because I was getting married the next day. She told me I could not possibly get married. However, I did get married but had to cancel the planned honeymoon.

7. My GP immediately referred me to a consultant and sent off liver function tests. On 18 January 1988 I was seen by Dr C. K. Harrison, a consultant haematologist at the Royal East Sussex Hospital in Hastings. My liver function readings were all through the roof, and Dr Harrison arranged for blood tests for Hep A and Hep B, which later came back negative.

8. I was considered to have contracted non-A, non-B Hepatitis from the blood transfusion and Dr Harrison reported this to the London Transfusion Centre. He told my GP that if she was not happy with my recovery progress to repeat the liver function test. He also referred me to a Dr Reid, consultant hepatologist on 19 January 1988 and I was seen by his registrar Dr S. Travis.

9. Dr Travis reassured my then-husband and I that there was no possibility of an HIV infection and that my husband (who was a nurse) could work normally.

10. He advised us to use barrier methods of contraception but that otherwise "Life will be normal, other than that I would need a lot of rest". The tests for Hep A not yet been received and the test for Hep B was negative but he said "I would be most surprised if this were not non-A non-B Hepatitis as a result of the blood transfusion." In a letter to my GP he said that he would be taking the appropriate steps to trace the donor.

11. Dr Travis reviewed me again on 9 February 1988, 29 March 1988, 24 May 1988 and 28 July 1988.

12. As my liver function tests had not returned to within normal limits as he had expected, I was then sent for a liver biopsy in early August 1988 which showed nothing sinister. I was then discharged and assumed that my liver had fully recovered.

13. At this time, I was also being seen by a consultant gynaecologist because of pain under the site of the original salpingectomy (left hand side). I was also experiencing very uncomfortable bloating.

14. For the next year I was not able to work at all and felt pretty ill and very tired a lot of the time.

15. In January 1989 I was referred back to Dr Reid's clinic because of a lot of abdominal pain which would knock me out for about two weeks. I saw a registrar – Dr Merchant, who thought that the symptoms could have been gallstones but that it was possible it was also caused by the hepatitis. I had an oral cholecystogram, which was normal.

16. Thereafter I used to ask my GP to do liver function tests every two years or so, which they did.

17. In early 1998 after I was divorced, I discovered that I had had a somewhat promiscuous boyfriend and my GP suggested that I go to the GUM clinic in Tunbridge Wells. I was called back to the clinic and was told that I had tested positive for Hepatitis C but negative for HIV. I was given very little information about it at that time nor was I then referred to any sort of specialist. There appears to be no record of this in my medical notes. I believe I was told that Hep C was transmitted blood to blood and therefore to be careful not to share toothbrushes etc.

18. Between 1989 and 1998 I was frequently suffering from pain and dull aches in my right upper quadrant radiating to my back, together with nausea and occasionally vomiting, which kept me awake at night. This is recorded in my medical notes. This continued until 2016 but I did not consult my GP about it after 1998 other than in 2016 when I was referred to a gastric surgeon. I never assumed it had anything to do with the original diagnosis of non-A non-B hepatitis but I now think that it was.

19. In late 1998 I moved away from the area and was registered with a different GP in Brighton for a period of 4 years~~.~~

20. In 2003 I moved back to East Sussex and re-registered with my old GP practice.

21. Around 2010 during a visit to my GP for something else, I mentioned that perhaps I should see a liver specialist to see how my liver was

doing. The GP admitted that he knew very little about Hepatitis C and that it would be a good idea to be checked over, so I was then referred to Dr Bird at the Maidstone Hospital whom I then saw annually until around 2015.

22. Dr Bird gave me adequate information about Hep C although by this time there was plenty of information on the internet.

Section 3. Other Infections

23. I have no other infections that I know of due to the HCV, other than gall bladder problems which have been rectified since the cholesystectomy. Research shows that there is a correlation between HCV and chronic cholecystitis.

24. I do suffer from vitiligo (loss of pigment in the skin) which my GP tells me is due to a compromised immune system and which is unsightly, especially in summer.

25. I am also prone to flu but receive an annual flu jab for this.

Section 4. Consent

26. Since I signed a consent form for the emergency salpingectomy at the Buchanan Hospital, presumably this consented to a blood transfusion, but I do not recall receiving any warning about risks associated with transfusions or information as to why I needed this transfusion.

27. Having now seen my medical notes, I see that I had had an internal bleed, with about 1.5 pints of blood in the abdominal cavity.

28. Any tests to do with the HCV have mostly been instigated by myself, between 1998 and 2010.

Section 5. Impact

29. In many ways I consider myself fortunate in that I was aware of the non-A, non-B Hepatitis at a very early stage and thus later able to proactively ask for my liver function to be monitored.

30. I believed at the time in 1988 that non-A non-B Hepatitis was simply neither Hep A nor Hep B and that it would clear up given time so I didn't really worry too much about it especially since I had been discharged from the hepatitis consultant.

31. However, discovering ten years later that I had in fact been infected with HCV back in 1987 was a nasty shock.

Physical and mental effects

32. Constant tiredness has been the main physical effect, as is vitiligo and recently peripheral neurasthenia. I always have aches and pains.

33. In October 2016 I had a cholecystectomy which greatly reduced the discomfort and bloating that I had been experiencing since 1989. A photograph of my liver taken during the operation showed cirrhosis according to the surgeon who performed the operation.

34. I have started to lose concentration and trains of thought and forget words frequently. I now find it difficult to do any sort of mental arithmetic which is frustrating in light of the fact that I have a degree in mathematics. To the medical staff I usually laugh it off as being down to old age but I don't really feel that is what it is.

35. I have always tried to be upbeat mentally and tend to put on a good face but having Hep C and now cirrhosis is and has been like a sword of Damocles hanging over me. I do not really disclose how I feel to anybody but I do worry inwardly about what might be around the corner

36. I am also fortunate in that I have a very positive outlook on life and am able to say to myself "OK you have some energy today, get on with doing something" or "golly I am tired so I will go and sleep for a few hours during the day"

37. Because I was on the more modern treatment, I experienced very few side effects from treatment received other than pruritus.

38. I do worry about the effect 30 years of an HCV infection has had on my liver and the lack of energy on some days whereby I just have to go and sleep, but I hope to live as long a life as my predecessors (my mother died aged almost 101 and my father at 98) but I try not to let it get me down. I also worry about finances and the fact that I find we need more and more help to do things that my parents were able to do well into their nineties.

Effect on family and social life

39. I have two grown up "children" and a loving husband who are naturally very concerned but I don't really trouble them with my worries.

40. We have a good circle of friends and I have not allowed by Hep C and subsequent cirrhosis to affect our social life other than the need not to drink very much. My friends all see me as having a lot of energy but they do not see that I still spend at least three hours during the day asleep and how early I need to go to bed at night.

Work-related effects

41. Looking back, I think my career would have been different, because I realise now that my constant tiredness and need to sleep for at least three hours in the day did have an impact on how much work I was able to do.

42. I set up and ran a market research company from 1991 onwards and fortunately was able to work mostly from home on a project by project basis and so was able to take the rest I constantly needed.

43. Prior to 1987 I had commuted daily from Sussex to Richmond and travelled for work around Europe with no problem and had extremely well-paid full-time work as an IT and marketing research consultant.

44. In 1995 I was offered a very good position with an eminent research company in London with excellent career prospects. I did take up full time employment with them for about two years – but had to give it up because I found the commute to London too tiring. I was also offered other very well-paid positions in London but I could not manage the long commute, so I worked for these companies on a freelance 1 to 2 day a week basis when I could. I am not sure whether my working life would have been any different, although I realise now that my constant tiredness did have an impact on how much work I was able to do.

Financial effects

45. My earning capacity was certainly diminished considerably after 1987 and never reached the same level again, so I definitely lost out financially.

46. Sporadic work did have the effect that I did not pay the full NI towards my pension with the result that it is extremely low (£382 every four weeks). I became very worried that I would not be able to manage financially in retirement.

47. For the above reason, I found it necessary to continue working in a part-time, fairly lowly position for a local Learned Society based in our village until I was over 72. It was only upon receiving the monthly ex-gratia payment from the Skipton Fund that I was able to stop.

Stigma

48. I have never experienced any stigma and I fully understand why, if I have to have any sort of surgery, I am last on the list. In fact, when I had a hip replacement, my surgeon told me that he would be performing the procedure himself because of the HCV. This had to be a bonus, really.

Section 6. Treatment/Care/Support

49. I have no criticism at all of the support and care I have received from the outset: from my GP; the Maidstone and Turnbridge Wells Trust; and from Kings College Hospital, to whom I was later referred. I would actually say that it has been exemplary since 2010.

50. I was also very quickly sent to a specialist when I first contracted non-A, non-B Hepatitis in 1988, who, from reading my notes, seemed to follow the correct procedures especially in informing the blood transfusion service in order to trace the donor.

51. My only criticism would be that perhaps I should have been referred immediately to a consultant hepatologist in 1998 when it was discovered that I had HCV. However, this could have been because I changed GP practice at that time.

52. I was finally referred to a consultant at my request in December 2010.

53. In July 2015 I developed a "fatty" liver and mild ascites. My HCV symptoms showed a degree of deterioration over the previous years in spite of liver function tests being relatively normal. I then researched and put myself on a special diet, and the next and subsequent scans showed that my liver was no longer fatty, although bloating and discomfort were becoming worse and very uncomfortable.

54. In January 2016 I was told that I could start traditional Interferon-based treatment and the side effects were explained to me, as was the fact that being a relatively nasty treatment there had been many patients who had not been able to tolerate it.

55. At a subsequent appointment with the clinical nurse specialist, she advised that if I was prepared to wait a few months it was likely that I would be able to have treatment with other new agents that would be superior and with less side effects, as long as my liver fibroscan showed that I had the right level of liver damage to qualify for this treatment.

56. My subsequent fibroscan showed a reading of 11.9 – meaning I bordered on cirrhosis and I started a 12-week course of antiviral treatment (Abbvie 3D and Ribavirin) in December 2016. Unfortunately, I did not obtain a sustained virological response, which was disappointing.

57. I was then referred to King's College Hospital to be considered for drug trials. I started a 24-week course of Epclusa and Ribavirin in December 2017 (but not a trial as I had expected) and this time obtained a sustained virological response.

58. Because at a more recent scan I had a pronounced portal vein, I am still under Kings College Hospital and continue to be monitored at the cirrhosis clinic every six months.

59. I have never been offered counselling or psychological support but having the sort of disposition I have I do not feel I have needed it.

Section 7. Financial Assistance

60. I received £20,000 from the Skipton Fund around the year 2000 and signed a waiver not to pursue a claim against the NHS (I believe this waiver no longer exists on current applications).

61. I received £50,000 from the Skipton Fund in November 2016.

62. I then received £1,250 per month from Skipton and now England Infected Blood Support Scheme (EIBSS), which increased to £1,500 in April 2018.

63. From April of this year (2019), I applied for a top-up income from EIBSS and received an extra £245 per month.

64. After the recent uplift, I now receive £28,000 per year and this is a great help since I find that I do need more and more help to run the house: my husband has COPD and can do very little. I still suffer from tiredness, inability to concentrate and "brain fog".

65. I have found the process of applying to the Skipton Fund and now to EIBSS quite straightforward and have only had contact by phone with them once when they were reasonably helpful.

66. However, I found it quite ridiculous that when I applied for an income topup and proved my current state pension through a letter from the Department of Work and Pensions that they then wanted a copy of bank account in order to see what the pension had been in the previous year and I pointed out that as they had the current figure, this was surely unnecessary since the previous year would have been a little less.

Section 8. Other Issues

67. I admit that I was sceptical of this Inquiry at the outset as a result of the Penrose Inquiry.

68. But, my attitude has now changed having seen or read some of the heart-breaking stories from others who have been so badly infected

and affected by this tragedy, and also the way in which it is being conducted so sympathetically by Sir Brian Langstaff.

69. I consider myself lucky to have received such good care from the NHS and I am grateful that I have the sort of personality that is able to just get on with life whatever it throws at you.

70. Resulting from this Inquiry, it would be nice to see:

  a. Some reassurance that at the very least the current payment schemes, upon which so many of us rely, will be guaranteed for the future.
  b. That GP's are better informed as to early symptoms of HCV and initiate tests for those at risk.
  c. That a system is put into place whereby this sort of thing can never happen again.

Statement of Truth

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

Signed GRO-C

Dated 13/08/2019