Witness Name: Stewart, Malcolm
Statement No.: WITN3288001
Exhibits: WITN3288002 - 3
Dated: 12-11-2019.

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MALCOLM STEWART

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 22 July 2019.

I, Malcolm Stewart, will say as follows: -

Section 1. Introduction

1. My name is Malcolm Stewart. My date of birth is GRO-C 1940 and my address is known to the Inquiry. I am a retired driver. I intend to speak about my experience with Von Willebrand disease and my exposure to vCJD through Factor VIII given to me at the time of an operation to remove a lung tumour. In particular, I would like to document how I have been treated since I have been notified that I am at risk of having vCJD.

2. To be clear, I have never been told that I am infected with vCJD. To my knowledge, I have never been tested for vCJD. I only know that I was exposed to a risk of vCJD.

3. This is because I received a discharge summary in November 2015 (**WITN3288002**) that notes "exposure to vCJD contaminated".

4. I have a letter dated February 2019 that shows how this is recorded: "possible exposure to vCJD". I have shown this letter to the investigators, and it is exhibited labelled **WITN3288003**.

Section 2. How Infected

5. From a very young age, I knew I was a "bleeder". I did not know that I had Von Willebrand disease until 1978, when I went to visit my brother at the Royal Free hospital. He had been diagnosed with Von Willebrand disease. While I was there, the doctor offered to test me.

6. The results of those tests showed that I also had Von Willebrand disease. I was put onto Factor VIII, which I have used since.

7. Prior to that, I just knew that I would bleed a lot, and that was that. When I was in the navy, there would often be blood in the boat when I got a bit hurt. It did not affect me that much. I even used to box at pubs because one was paid £5 for taking part! I would bleed a lot, but that's the way it was.

8. In 2000, I was working on a job using a jackhammer. I pulled three disks in my back. I was admitted to the Royal Free Hospital.

9. Professor Lee at the Royal Free referred me to an orthopaedic surgeon who referred me for an MRI scan.

10. When I came out of the "tunnel of love" (as I call an MRI machine), I was told that I could not have my back operated on as I had lung cancer.

11. I remember Professor Lee telling me that I was very lucky that the lung cancer had been detected and that they could operate to remove it.

12. I had the operation to remove the cancer the next day. A top surgeon from Middlesex Hospital did the operation. They told me that I'd need six pints of "the glue" in order to thicken my blood. "The glue" is Factor VIII. This is when I believe I was exposed to vCJD.

13. After the operation, the surgeon told me that it had gone very well. I never did get around to fixing my back!

14. In about 2002 or 2003, I had been seeing a lot of consultants due to the cancer. I received a letter from the Haemophilia Centre informing me that the person who donated blood to me died of vCJD and that I may be infected.

15. The letter went on to say that I cannot go to a dentist outside of the NHS, and that I must inform all healthcare professionals that I may have vCJD.

16. It also said that any medical instrument used on me had to be destroyed as the bug never dies.

17. It also said that I should be careful in my sex life. Beyond that, I was provided with no information.

18. They did not recommend that I undergo any tests. When I asked the doctors how I would know if I was infected, I was told that cannot know. To this day, I do not know whether I was or am infected with vCJD.

19. Some time after this, I went to the Royal Free Hospital to see the Ear, Nose and Throat specialist. I gave him the letter that detailed my possible exposure to vCJD – as I always did when I saw healthcare professionals.

20. He asked whether he should put it in my medical notes that I had been exposed to vCJD. I said that he could. As it turned out, that was the biggest mistake of my life.

21. From that day on, no clinicians wanted anything to do with me. My appointments would be cancelled and I felt that this was because they saw me as contaminated.

22. I eventually went to the Royal Free Hospital and said "either I have vCJD or I don't" and asked when I would find out. I was told that they will know when they do the autopsy.

23. Shortly after that, in about 2012, I received a letter from the Ear, Nose and Throat specialist requesting me to come in for an appointment. I was not told what the appointment was for.

24. I arrived at the Royal Free Hospital for the appointment and was asked to strip off my clothes and put on a gown. I asked why I was at the hospital and was told that a tumour needed to be taken out of my throat.

25. This was a surprise to me. Nevertheless, I had the operation.

26. Once I came to after the operation, I was told I would have to stay in the hospital for a week to recover because I had bled a lot during the operation.

27. I was put into the isolation ward on the ninth floor of the Royal Free hospital. Before I got there, the nurses were lined up. I remember them saying "we don't touch him". They all refused to come near me or to administer Factor VIII to me.

28. A friend of mine and his wife came to visit me at the hospital. While they were there, I asked the nurses why they wouldn't administer the Factor VIII to me.

29. One of the nurses told me that they cannot administer the Factor VIII and recommended that I go to "a good haemophilia centre like the one at UCH" (University College Hospital).

30. Since about 2014, I have been attending at UCH. I have seen multiple consultants. I am constantly sent for tests – some at UCH; some at cancer clinics; some at various other places – but I never see the results or the referring consultant again. I have probably seen two hundred different consultants over the years.

31. Not too long ago, I was sent for an endoscopy at UCH. After a few weeks, I went to see a haemophilia consultant at UCH and I asked for the results. He said that it was all clear. This was very strange, I pointed out, because I had a growth protruding from my stomach.

32. The consultant arranged to have it removed. When I went to the stomach surgeon, a lovely woman, she asked if I have any other problems. When I said that I was a haemophiliac, she told me to "get out" because they "can't have [me] bleeding all over the place."

33. I was transferred to the cancer clinic where I was given Factor VIII. I was never told what the growth was.

34. I have had many incredibly frustrating interactions with the NHS. After a recent episode to do with my stomach, I was so frustrated that I stopped taking all of my drugs, though I have since started taking them again.

35. The episode began with my receiving a letter telling me to attend at UCH for a consultation with a stomach specialist. When I arrived, I shook the clinician's hand and he said "I'm your surgeon".

36. This confused me a lot as I had no idea that I was supposed to be having surgery. He said "You may have cancer" and that he needed to send me for some tests.

37. I then got a letter from a stomach specialist asking me to attend at an appointment. I went reluctantly. He asked me about the reflux that I suffer from. I told him that it is as bad as it has always been: I battle with it for about half of each week. He did nothing much and then said "See you when I see you".

Section 3. Other Infections

38. I do not believe that I have received any infection or infections other than vCJD as a result of being given infected blood or blood products.

39. I know that when I was fifteen (in 1952), I had tuberculosis. One of my lungs was removed during a lobectomy. It is likely that I had to be given blood then.

40. That said, I do no remember being told of any transfusions.

Section 4. Consent

41. I do not believe that I have been tested without my consent despite the fact that I am sent for tests often for a variety of things. I see neither the results nor the consultants who sent me.

42. I remember that when I was a young boy, the doctors did not know why I was bleeding. They wanted me to go to Western Hospital to be studied. That never happened.

Section 5. Impact

43. I have a lot of pain. I am in pain from the moment that I wake up.

44. I cannot stand up to cook a meal. I live on tins of rice and tins of soup.

45. After I make a cup of tea for myself, I have to lie down.

46. I used to be in so much pain that I would drink to numb it and drink to allow myself to sleep. I drank a lot of whisky.

47. I spend half the night sitting on the toilet passing water.

48. I never had much money, but my ill health has financially ruined me. I have not been able to work productively.

Section 6. Treatment/Care/Support

49. I remember being advised at some point that I should be careful in my sex life because of the chance of transmitting the disease.

50. I was never offered any treatment or counselling.

51. In fact, the investigators are the only people I have ever spoken to about this.

Section 7. Financial Assistance

52. I have never received any financial assistance. I did not know that any schemes existed.

53. The investigators have informed me about EIBSS. I may apply to the scheme.

Section 8. Other Issues

54. My brother died from Hepatitis C. I did not know that he had Hepatitis C until he died nor did he know. I have never seen his saw his death certificate so I do not know what is officially recorded as his cause of death. He was about 65 when he died, and he and also received Factor VIII from the Royal Free Hospital.

55. My brother's family was told that he drank too much, but this was not the case. He did not drink heavily.

56. Two of my brother's sons were haemophiliacs. One died of Hepatitis C after receiving blood products. I never saw his other son.

57. I wish that I had never had that cancer surgery. I feel that my health has never recovered.

58. I feel very frustrated and disillusioned with the quality of medical care that I have received. It does not feel like the clinicians actually want to help me. If they did, they would meet with me again after the initial consultation.

59. Every six months, I went to the stomach specialist at the Royal Free Hospital, Dr GRO-D. He gave me the same medication although I toldl him I really do not feel that I am in good health.

60. When I eventually said to him that I am not coming back because I do not feel he does anything for me, he sent me a letter recording that I had said that.

61. This was not a surprise to me. I was used to cancellations – they were very normal for me. It showed me that there was no real care. It was all about ticking the boxes. I have had enough.

Statement of Truth

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

Signed GRO-C

Dated 12-11-2019.

ITS, PERFECTLY TRUE THANKS.