Witness Name: Joan FOORD
Statement No. WITN0868001
Exhibits: WITN0868002 to
WITN0868010
Dated: 30 / 07 / 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF
JOAN FOORD

I provide this statement in response to a request under Rule 9 of The Inquiry Rules 2006, dated 12th March 2019.

I, Joan FOORD, will say as follows:-

Section 1 Introduction

1. My name is Joan FOORD and I was born on GRO-C 1955. I live at an address in the South of England that is known to the inquiry. I am employed as an area manager for the St John Ambulance Brigade, and have previously been employed in a payroll and accounts office and for a builders' merchant.

2. I intend to speak of my late husband, Denis George SOAN (born: GRO-C 1951) and his infection with Hepatitis C (also known or referred to as HcV and / or Hep' C). Denis was a haemophiliac who was infected as a direct result of his using blood products as a means of treating his blood disorder.

3. I intend telling the inquiry of the nature of his illnesses, how the HcV infection affected him, the treatment he received and the impact which Hepatitis C had on him and our lives together. Denis died on 1st May, 2004 at just 53 years of age).

4. Denis and I married in 1976. We were both young, but decided not to have any children of our own. One aspect of this was the fact that Denis had haemophilia, and he was acutely aware of the suffering a haemophiliac child had to endure, as he had, and didn't want a child to suffer if he could prevent it, which we did.

5. My late husband had Haemophilia B, where there is a lack of the Factor Nine clotting protein, which is relatively rare, even amongst the haemophilia community.

6. The Infected Blood Inquiry have informed me of the anonymity process for witnesses, but I do not wish to provide my evidence anonymously – I want Denis, through me, to have his say in what happened and for his voice to be heard.

Section 2 How Infected

7. Denis was an hereditary haemophiliac, born with what is known as Christmas Disease or Haemophilia B. He received treatment, as and whenever he suffered a bleed, with a product called REPLENINE, a blood product, as he could not produce enough of the Factor Nine blood clotting protein himself.

8. As a haemophilia patient, Denis was issued with a card, a 'Special Medical Card' which he had to carry with him at all times. It had been issued through the Haemophilia Centre of the Royal Sussex County Hospital, and basically said who he was, where he lived, what his condition was, and what he was to be treated with in the event of a bleed.

9. The card also held details of his General Practitioner (G.P.) and Haemophilia Consultant, together with an emergency contact number. The idea behind it was that, in the event of any emergency treatment being required, the clinical staff dealing would be able to see from the outset what they were dealing with, in addition to whatever may have happened to him, and act accordingly. If they didn't know what to do, the emergency number was there for them to seek appropriate advice.

10. A copy of this card I now produce as my Exhibit WITN0868002.

11. Throughout his adult life, Denis was placed under the care of a Dr. Martin W. KENNY, a Consultant Haematologist of the Royal Sussex County Hospital. He was 'with' Dr. Kenny from at least 1984 until his death, 20 years later.

12. Denis Soan was someone who from birth had been exposed to the risk of infection as a consequence of the amount of blood products he would have had to take whenever he suffered a bleed. I would estimate that as an adult alone, he had to be given Factor Nine approximately two or three times per year.

13. I am unaware of what, if any, information Denis may have been given as to the risk posed by his continual use of blood products, as I did not accompany him to any of his appointments, and as he had been born with Christmas Disease, I cannot comment on any discussions as to 'risk' that may have taken place whilst he was a child – be that with him, or his parents – he may have been told, but then again, he may not.

14. Whatever the case may have been, using Factor Nine was literally a 'life-or-death' situation Denis, whenever he took a knock or bumped himself he bled, and there were no other ways of treating his bleeding which happened each time – he had to be given Factor Nine to control the bleeding. He really had no choice to make as to whether or not he had it, even if it came with the risk of infection, as he would have continued to bleed out without it.

15. Every six months, Denis had to see Dr. Kenny for a routine monitoring appointment. This happened 'as a matter of routine' for many years until 1995 when apparently as a result of concerns over an infection issue, he was called in for an additional appointment.

16. Denis went to the Haemophilia Centre and had some blood taken for testing. Shortly thereafter he received a letter, dated 27th April 1995, through which Dr. Kenny gave him the blood test results. He had been tested for both HIV and Hepatitis C, and was found to have contracted Hep C.

17. The letter described how the HcV diagnosis would have explained mildly abnormal liver tests he had also undertaken, but that all he would recommend was that they 'keep an eye on it' until repeating the tests three months later (when he was due to attend for a routine bi-annual appointment in his clinic).

18. The doctor sent the letter alongside a leaflet produced by the Haemophilia Society about hepatitis which apparently contained all that was then known of the disease.

19. I do not have a copy of the leaflet, but a copy of the letter I now produce as my Exhibit WITN0868003.

20. I am not sure just how Denis felt having received such a letter, being told 'by post' as opposed to 'in person,' but he did have a good, long-standing relationship with Dr. Kenny, so if he had had anything to say on the matter, he would have said it to Dr. Kenny himself.

21. Both Denis and I had been volunteers with the St. John Ambulance Brigade for some years, and were aware of the precautions we would have to take to prevent the risk of any cross infection, in particular Denis and the risk he posed to others.

22. For the final eight to nine months of his life, Denis and I were able to hold a stock of the clotting factor in our home. We had a special fridge to keep it in, as it had to be stored at a certain temperature, and we were given instructions as to how to administer it were that to become necessary.

23. We also had written (printed) information as to what to do. A copy of the information I now produce as my Exhibit WITN0868004. This information was bespoke to Denis Soan and had been prepared by or on behalf of, Dr. Kenny.

24. Whenever Denis suffered a bleed, I would prepare the Factor Nine and pass it, with the instructions, to the emergency services and / or hospital so that they could administer it to him (through a cannula into a hand, which they would have to insert).

25. There was an assumption that he had been infected through product use, but I don't recall him ever having been specifically told that he had been infected by any specific batch or by factor products in general.

26. However, I was fully aware, from what Denis had told me, that he had been infected by blood products, and he would have known and had any related conversations with the medical authorities, in particular Dr. Kenny.

27. He had taken them every year of his life, without exception, in so far as I am aware. However, neither of us knew when he had been infected, in part because his liver functioned so well, for so long, we had no reason to suspect infection, and then no means of 'pinning it down' to any particular dose.

Section 3 Other Infections

28. I do not believe that Denis was ever infected with anything other than HcV from his use of blood products.

Section 4 Consent

29. Denis would often volunteer to be used as a 'training patient' for medical students and young doctors, as both Haemophilia B and Hepatitis C were rarely encountered. When he was needed, the hospital would send a taxi for him, and he'd then travel to the hospital and help instruct around 9 or 10 doctors at a time.

30. I do not believe that Denis was ever treated or tested without his knowledge and consent, be that as regards his own treatment or for research purposes, but I do not know if he was used as a case study for research, or not. I do not believe that he was ever treated in the absence of his having been given full and adequate information.

31. Consent was always given as regards any treatment or tests he may have needed, but in so far as his use of Factor Nine is concerned, consent wasn't an issue, he simply had no other choice.

32. As an integral part of his HcV treatment, Denis was to be given a liver transplant, something he was able to go into with his eyes fully open, being fully aware of the risks posed and what the procedure, its preparation, and aftercare involved. The hospital gave him all of the relevant information and we felt that we could ask them anything we needed to, and did, and trusted them.

33. This approach was in stark contrast to the somewhat paternalistic attitude of clinicians across the rest of his medical history where you just trusted the doctors without question, and do what you were told or asked to do.

Section 5 Impact

34. Following his diagnosis in April 1995, his daily life did not alter drastically. He continued to work and volunteer with the St. John Ambulance. He was then working in Crawley, which required him to make a daily journey of an hour each way. He continued to function normally, and continued leading camps almost until he died, having just cancelled one trip towards the end.

35. However, as time progressed, he found himself becoming more and more tired than had been usual, and moving into the early 2000's, his health began to deteriorate, and was getting noticeably ever more lethargic throughout his late forties.

36. Denis was 53 at the time of his death, and towards the end of his life he became jaundiced and looked gaunt, but as he had suffered health problems throughout his life with the haemophilia, he had become very resilient and rarely complained. When he was tired, he rested, but otherwise he was quite a 'live wire.'

37. HcV affected his liver which continued to deteriorate as time went on. In 2003 it had become so bad that he was referred to a Dr. TIBBLE. By now his condition had deteriorated to a point where he had to be monitored in clinic every three months by both Dr. Tibble and Dr. Kenny.

38. On 23rd July 2003, Denis was admitted to hospital having sustained a stomach bleed and having had fits. He was transferred to King's where he had to remain as an inpatient for some eleven days, much longer than usual with a bleed which usually saw him kept in for no more than a day or two, if that.

39. The regular monitoring by Dr. Tibble and Dr. Kenny revealed a continuing deterioration of the liver, and he developed cirrhosis to the extent that he required a transplant. As of 23rd January 2004, he was listed for a liver transplant at King's, and waited for a donor liver to become available and for him to 'move up the list.'

40. It was whilst he was waiting for his transplant that Denis wrote a letter to his colleagues in the St. John Ambulance Brigade, encouraging them to register as organ donors and explaining a little of his condition and in particular about Haemophilia A and B, blood clotting disorders, HIV, HcV and their treatments. He also provided some statistics pertinent to liver transplant patients of that time.

41. This letter I now produce as my Exhibit WITN0868005

42. In January and then again in February 2004, livers became available, but neither were found suitable for Denis to receive. Having been contacted and taken to the hospital, by ambulance, each time, only to leave disappointed served to put things into perspective, and Denis even drafted his last will and testament on one occasion, whilst en route to the hospital, he clearly thought that he may die, with or without a replacement organ.

43. In March 2004, a third liver was secured for Denis and he went into King's again, hopeful that all would be well, but during surgery the doctors found that Denis had developed Hepatocellular Carcinoma (liver cancer), and as such was an unsuitable recipient – he couldn't have the liver as you cannot take anti-rejection medication at the same time as receiving cancer treatment, they are incompatible, so he was disappointed again and found that he had another medical issue to address.

44. Apparently, liver cancer is often a progression from chronic cirrhosis of the liver, and in his case was a progression of the HcV induced liver issues he faced.

45. On 24th April 2004, Denis was admitted to the Brighton Hospital and died just a week later on 1st May, 2004, a direct result of the cancer in his liver having spread. His death certificate recorded the cause of death as having been Hepatitis C infection, Hepatocellular Carcinoma and Haemophilia.

46. I now produce a copy of the death certificate for Denis George Soan as my Exhibit WITN0868006.

47. I am unaware of any treatment Denis may have been given to treat or arrest his condition, other than those he received.

48. In 2001, Denis had had to have a tooth extracted – he was then known to have HcV, but I do not recall him having been treated differently to anyone else as a result of his infection, but he would nevertheless have had to have attended hospital the day before, to be given some Factor IX prior to the procedure being carried out.

49. In around 1980, before his Hepatitis C status was known (and at a time when he may not have had it), Denis had to have his varicose veins operated on, in Brighton. He was a known haemophiliac, and treated as a haemophilia patient with the hospital having prepared in advance by 'buying in' sufficient stocks of Factor IX for him.

50. Fortunately the operation was a success, with only a little Factor IX having been used, but I recall the doctors having told me post-operatively that luckily, they had bought the blood product on 'sale-or-return' from France, so they were going to return the unused stock to recover some money. I was uncomfortable with this, and if nothing more, it made me wonder where the stocks which were being used had come from.

51. Denis' treatment in hospital was largely very good. There were mainly only issues with the speed of his being seen when he had suffered a bleed, as time was of the essence in providing Factor IX, the longer the delay, the more severe the bleed, the longer the recovery period. I learned that you had to be fairly proactive in this regard, in order to be seen with any sense of urgency.

52. There seemed at times to have been a lack of knowledge of haemophilia. I distinctly recall two junior doctors racing to treat Dennis so as to have been able to record that they'd treated such a patient upon their training records.

53. Fortunately, Denis and I had a good friend who worked in our local Accident & Emergency (A&E). Whenever she was on duty, she would help us to get the ball rolling, ensuring the correct treatment for his bleeds and bruises following knocks, bumps or falls.

54. Financially, things weren't ideal, but could have been worse. Denis had been a pension contributor with his employer, the St John Ambulance Brigade, and as he died whilst in service, his pension (or a proportion of it) came to me, and by this time our house had been paid for (something I did following an inheritance).

55. When Denis died I was still or working age and worked on for another 15 years at an accounts and payroll office in my local village. Other pensions also 'paid out,' and provision had been made for me within them.

56. Socially and domestically I was fortunate to have a good circle of friends, without whom I would not have been able to cope. I had friends in our local pub', and remarried, marrying a long-standing friend of both Denis and I.

57. I think that the impact of Denis' death was most probably made easier by our knowing that it may have happened, having discussed it together and with friends, and prepared. With his HcV diagnosis, and then the liver issues and a lack of a transplant, I believe that he knew it was inevitable. He asked to be cremated, and now rests at peace in our garden.

Section 6 Treatment / Care / Support

58. Denis was never offered any treatment for Hepatitis C. He was given regular liver check-ups, to assess the progression of the infection, but that was all. There was no treatment available to him at that time, and no trials of medication which may have helped, were offered or made apparent either.

59. Denis having cancer proved to be the largest obstacle to his being given any form of treatment, as it directly resulted in his being unable to receive a donor organ, but he experienced no barriers to treatment as a result of his HcV or Haemophilia B status.

60. We did not receive any counselling as we did not think it suited us. We were able to prepare for the inevitable, as best we could, together and as individuals.

61. People were very supportive – they would phone to check upon me and how I was coping. I benefitted from a good circle of family and friends, and help was always offered but didn't feel the need to take it up.

62. I am aware that psychological support may be available for witnesses through the Infected Blood Inquiry, offered by the British Red Cross.

Section 7 Financial Assistance

63. On 18th June 2004 a letter was sent to Denis from the Department of Health, announcing their launch of an ex-gratia payment scheme called The Skipton Fund. Denis had passed away six weeks before.

64. The letter came with an application form, which I completed and returned, and on 30th September 2004 received a payment of £20,000-. However, the letter accompanying the payment was again addressed to Dennis, notwithstanding the information I had put in the application to the effect that he was dead. The payment was also payable to Denis.

65. This was extremely frustrating as all of his accounts had, by then, been closed and it should all have been handled in my name, not his – it made me question the competence of the scheme and those who ran it.

66. I received a second payment, this time for £25,000- on 26th January 2005, which was followed by a further £25,000- Phase Two payment in April, 2011, a remittance notice for which I now produce a copy of as my Exhibit W0868010.

67. I now produce a copy of the initial application form as my Exhibit WITN0868007.

68. I now produce copies of the remittance notices regarding the first two Skipton Fund payments as my Exhibit WITN0868008.

Section 8 Other Issues

69. In late September 2004, I received a letter from Dr. Kenny of the Brighton and Sussex University Hospitals NHS Trust, Denis' Consultant Haematologist. In the letter he paid testimony to Denis and referred me to the Skipton Fund, it arrived shortly after I'd received the first payment.

70. I now produce a copy of the letter of Dr. Kenny (dated 17.09.2004 / 23.09.2004) as my Exhibit WITN0868009.

Statement Of Truth

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

Signed: GRO-C

Dated: 30 / July / 2019