Witness Name: Susan Lesley Nicholson
Statement No: WITN1433001
Exhibits: 0
Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SUSAN LESLEY NICHOLSON

I, Susan Lesley Nicholson will say as follows:-

Section 1. Introduction

1. My name is Susan Lesley Nicholson and I was born on GRO-C 1954. I live at GRO-C Darlington, GRO-C

2. I am married and both my husband and I have retired. I am not receiving state pension yet as I am not of retirement age.

3. I write this statement on behalf of my late husband, Dennis Cattley born on GRO-C GRO-C 1949. Dennis died at the age of 49 on 25 March 1999 from liver cancer as a result of contracting Hepatitis C (Hep C) from infected Factor VIII (FVIII) blood products.

4. Dennis and I have 3 children together, one son born in 1981 and twin sons born in 1985. GRO-C GRO-C

5. This witness statement has been prepared without the benefit of access to my late husband's full medical records.

Section 2. How Affected

6. Dennis was diagnosed with Haemophilia when he was just 6 months old. Later, in the 1970s it was confirmed that he had severe Von Willebrand's disease.

7. In the late 1950s and early 1960s, Dennis used to have regular nose bleeds and therefore was in and out of St James's Hospital Leeds (SJHL) on a regular basis. There was no treatment for Dennis' health condition apart from bed rest and packing his nose to stop the bleeds. He regularly received blood transfusions and several times the doctors thought Dennis would die as a child. When he was about 9 years old he was admitted to Wharfedale Children's Hospital (WCH) in Yorkshire where he stayed as a permanent resident for about 2 years.

8. I met Dennis when he was 21 years old in 1970. I believe from about this time he was given Cryoprecipitate to clot the blood. They told him that this agent will encourage the body to produce its own clotting agent. It was kept frozen so whenever Dennis had a bleed, the doctor would defrost it and administer it at hospital.

9. I believe Dennis was first given FVIII in or about the early 1980s at SJHL. He was mainly under the care of Dr Swinburne

10. When our eldest son was born in 1981, both my husband and GRO-C were given vaccinations against Hepatitis B (Hep B). I did not question the doctors at the time and just trusted them.

11. When we went on holiday to France in 1989, we were given glass bottles of FVIII powder to take with us in case Dennis had a bleed so that we had treatment for a doctor to administer. We were given a letter to take with us to confirm the treatment and get the drugs through customs.

12. In or about the 1990s I recall that I started to administer FVIII at home. I was trained by the nurse in the Haemophilia Centre at SJHL. It made life much easier when I was able to administer it at home. We were given glass bottles

of FVIII powder, sterilised water, needles and syringes. We were told to mix the powder and the water together and then inject it.

13. We were not told much about the FVIII other than the fact that it was a 'wonder drug' that would change Dennis' life. We trusted the doctors and did not have any reason to question them.

14. I do not believe that Dennis was provided with any information or advice beforehand about the risk of being exposed to infections as a result of using FVIII. I believe that he should have been told that there was a risk. Even after the doctor's found out about the Hep C, I believe we were still not provided with adequate information. I was not provided with any information or advice beforehand.

15. I believe that Dennis was told he had Hep C in or about the late 1980s/early 1990s. However, I believe that the doctors knew about his Hep C status before he was told. Unfortunately, I cannot remember the exact date that he was told. I do not think we ever sat down and had a discussion with the doctors about the test results and what it meant for Dennis. I do not believe Dennis gave his consent to be tested for Hep C. At the time, we just picked up information from the media and then started questioning the doctors.

16. I do not believe that Dennis was provided with any information about how to manage the infection. I was not provided with any information in this regard.

17. The doctors did not even inform us about the risk of transmitting the infection through sexual intercourse. I only realised that Hep C could be transmitted when I read a blood form prior to donating blood. I was not able to donate blood and was embarrassed by having to leave the donor session under these circumstances.

18. The above form had questions asking whether I had a homosexual husband, whether my husband is a Haemophiliac or a drug user. They classified Haemophiliacs with other drug users and undesirable people which I was disgusted about.

19. In 1999, Dennis was told that he needed to have an operation in order to remove a tumour from his liver. He had previously been told he had scarring on his liver. We were not really given a choice as the doctor explained that if he did not have the operation, he would die within 2 months. Therefore, we agreed to the operation. He told us that the operation had risks but that if he survived the operation he would recover as the liver would regenerate itself. It never occurred to us that if he survived the operation, he might die.

Section 3. Other Infections

20. In 1987, Dennis was diagnosed with diverticulitis and I do not know if it was as a result of the Hep C.

21. In 1999 he also developed an extensive Hepatoma (cancer of the liver cells) occupying 70% of the liver volume. Unfortunately, he died in the immediate post-operative period after attempts to resect it.

22. Dennis had tests in hospital prior to the liver operation in March 1999 and he required a blood transfusion (a couple of pints). In a matter of few minutes, he started itching and his body swelled up. The nurse did not even react and told me that Dennis must have been allergic to the blood from the donor. Then she gave him an injection to counteract the reaction before giving him another blood transfusion. It was so casual and we were not provided with any information as to what exactly happened or what the infection was.

Section 4. Consent

23. I believe that Dennis was tested without his knowledge, consent and without being given adequate information. As previously stated, at paragraph 15, I do not believe that Dennis gave his consent to be tested for Hep C specifically. They just did regular blood tests. I do not know if Dennis was treated or tested for the purposes of research.

24. I believe that the doctors knew that FVIII was infected with Hep C and failed to tell Dennis beforehand.

Section 5. Impact of the Infection

25. The infection impacted Dennis mentally. In or about 1987, Dennis was sick and had flu-like symptoms. When we went to the GP, he was diagnosed with diverticulitis and he was told his bowel was bleeding internally. He was admitted to SJHL and put in a side ward and the staff came in with gloves and masks and kept him away from patients. We thought this was very strange. We were both made to seem like lepers. They treated Dennis as if he had AIDS even though they knew that he was infected with Hep C. This caused us a lot of mental distress.

26. Dennis tried to keep his emotions to himself and never mentioned it to anyone new that he had Haemophilia (Von Willebrands) as he did not know how they would react with all the media coverage about AIDS and Hep C. He just got on with life when he found out about the infection as he knew he could not do anything about it. He wanted to live a normal life as if nothing had happened. I do not think Dennis grasped how dangerous the infection was and neither did I. I believe he did not think it was going to affect him any more than his Von Willebrand's disease.

27. The Hep C also had a big physical impact on Dennis. He was always tired and lethargic. At the time, he had 2 jobs and later on in the last couple of years before his death he worked in a call centre for extra cash. Our impression was that he was tired due to working too much but we only found out later that it was actually the Hep C that caused the above symptoms.

28. Dennis had a big stomach and his face was very gaunt. We later realised that his distended stomach must have been the tumour on his liver. The doctors were monitoring Dennis' liver and he had blood tests once a month to test his liver functions. The doctors always asked if he was a big drinker as they said that the scarring of his liver could be caused by heavy drinking. We did not believe this as he did not drink. This was upsetting as they knew he contracted Hep C from the contaminated FVIII blood products that they gave him yet were trying to say the 'scarring' was as a result of drinking.

29. Towards the end of 1998 and in the beginning of 1999, Dennis was told he had a tumour on his liver. The doctors said the only thing they could do was to operate on the liver to get rid of the tumour and that the liver would regenerate. After the operation, Dennis was bleeding profusely and was given a lot of FVIII to try and stop the bleeding. His kidneys then failed so he was put on a dialysis machine but because of the clotting agent he was given, the blood in the dialysis machine clogged up, so it was turned off. He was then kept in an ICU on life support machine for a fortnight, as he did not regain consciousness. We turned off the machine as he was obviously bleeding to death and they could do nothing to stop it. We did not want to see him in pain any longer and then Dennis sadly died.

30. It came as a shock to me that the doctors took a huge risk on him, despite telling me that if he had this operation, his liver would regenerate and that he would be fine. I never expected him to die after the operation.

31. I do not believe Dennis was given any treatment or medication for his Hep C. I do not know whether there were treatments which ought to have been available at the time.

32. Dennis' infection impacted us as a family on our private life as well as our social life. We did not discuss this situation with my parents or Dennis' parents. We only ever spoke about his Von Willebrand's disease. No one made us aware how serious Hep C was. We certainly did not speak about it to anyone other than close friends and family and certainly not colleagues at work as he was scared of their reaction.

33. The media did not help at that time either as it portrayed an image that you could catch the infection from touching people, using the same toilet seats, sneezing or even sharing a glass. A lot of scare mongering was going on at that time. We just got on with it without talking about it to anyone although many people knew about his Von Willebrand's disease from earlier on.

34. The fact that Dennis died as a result of being given contaminated blood products really upsets me. If he was not given the contaminated blood

products, he would not have got liver cancer and would not have died leaving his 3 young children behind. Thinking about it makes me very tearful as I never really got over his death.

35. Our children were really affected by their father's death. The twins were only 13 years old and our eldest son was 17 years old and watching your father die in front of you is very hard. This was a very hard time for the children to lose their father when they needed him the most.

36. We did not tell the children about Dennis' Hep C as they were too young to understand. However, they were always aware that their father had Von Willebrand's disease and they have seen me administer FVIII to him at home.

37. Our children never thought that their father was going to die. They knew he was going to have an operation but we all assumed he was going to get better and that everything was going to be fine.

38. In terms of work-related effects, Dennis just carried on working until his death. He never let the infection stop him from doing what he wanted to do. A lot of other children in the special school he attended (Potternewton Mansion, Leeds) who were Haemophiliacs were treated as if they were wrapped in cotton wool, but Dennis just wanted to live his life. Lots of those children have also died as a result of the infected blood. As a young person, he was brainwashed to believe that he could not have a family but he had 3 children with me and he was really happy.

39. Throughout his childhood, Dennis had so many transfusions to the point that when he was older, people used to think he was a drug user as he had lots of scars on his body.

Section 6. Treatment/care/support

40. As previously stated, I do not believe Dennis received any treatment for his Hep C.

41. I do not believe Dennis was offered any counselling of psychological support. I believe that if it was offered to him it would have helped him understand and manage the infection.

42. I was never offered counselling or psychological support at the time, or after Dennis' death. I believe if it was offered to me and my children, we would have greatly benefitted from it by talking through how if affected us, but we never got that opportunity.

43. After his diagnosis, we never heard from the doctors again asking how we were coping as a family. There was no support at all.

Section 7. Financial Assistance

44. I received both the Skipton Stage 1 payment in the sum of £20,000 and Stage 2 payment in the sum of £50,000, totaling £70,000

45. I also received a one-off payment in the sum of £10,000 for bereaved spouses in 2017 from the department of health via the Skipton Fund.

46. Dennis did not know anything about what financial assistance, if any, was available to him. No information was provided to us at the time.

47. I only found out about the Skipton Fund as my son, who still lives in the house we lived in when Dennis was alive, received some post from the hospital. My son received a letter from SJHL in 2011, which was addressed to 'the family of the late Dennis Cattley'. If my son had not lived there I would never have known about the Skipton Fund as I was unaware of such financial assistance, until I received the letter.

48. The application for financial assistance was simple and straight forward, apart from the fact that it was quite difficult to find proof that I lived with Dennis when he contracted Hep C as it was so long ago.

49. The Trusts and Funds do not describe these payments as compensation but as financial assistance. We should really be compensated for the loss we have suffered.

50. I started to get £750 a month top up from EIBSS last year as our family income is below the certain thriving scale. I am still currently receiving the above amount. This financial assistance is means tested and reviewed each year, which I believe, is wrong and degrading.

Section 8. Other Issues

51. From this Inquiry, I would like to get some answers. I want to know why the hospitals carried on using infected blood products even though I believe they knew it was infected by the 1980s. I want to know who made the decision to carry on using infected imported blood products. I want the people responsible to be held to account for what they did. I would like to see some justice for the people who have suffered like me and our three children. I will never be able to get over it.

Anonymity, disclosure and redaction

52. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

53. I do not wish to give oral evidence at the Inquiry.

Statement of Truth

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

Signed......... GRO-C .....

Dated 14/02/2019