

Witness Name: Pauline Nicholson

Statement No.: WITN0079001

Exhibits: NIL

Dated: 18 December 2018

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF PAULINE NICHOLSON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 3 December 2018.

I, PAULINE NICHOLSON, will say as follows: -

Section 1. Introduction

1. My name is Pauline Nicholson. My date of birth and address are known to the Inquiry. I am a retired bookkeeper from a building firm in Portsmouth, although I am now a full time carer for my husband. I am married with two children. My eldest is 62 and my youngest is 59. I was born with Von Willebrand's (VW) disease. In this statement I intend to speak about my Hepatitis C infection (HCV), which I contracted after receiving Factor VIII. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on me, my family and our lives together.

Section 2. How Infected

2. I have Von Willebrand's disease and I think I must have been born with it. I would say it is mild. If I bumped my knee I would not have problems. If I cut myself then it would bleed, but I had a nosebleed when I was little and I would have to pinch it and so on. I never needed any blood or blood products prior to 19 November 1983.
3. My husband is a retired butcher. On 19 November 1983, I had an accident where I sat on my husband's boning knife. It had been left out of its sheath in the front of the car, and had fallen down the side of the seat. I was working at the time in a residential home for teenagers with disabilities and it was Christmas. I jumped in the car and sat on this knife and it cut the back of my upper thigh.
4. We went to the local hospital at Ascot and they said they could not do anything. They padded me up and my husband drove me from Ascot to the Radcliffe in Oxford. I sat in the car holding the padding to my thigh to help stop the bleeding.
5. We got there and I was put into this little room. One of the medical staff came in and I was given an injection, not being told what it was or what it was for. I now know that this injection was Factor VIII, but at the time I was given it I was not made aware. After the injection, I was given some stitches. They then put some plastic knickers on me and said I could go home and that I should continue resting. My husband drove me home.
6. Two days later on 21 November 1983, Dr Matthews (from Oxford) phoned me and informed me that I required blood tests for the next 12 weeks because they were worried about jaundice. I then rang my doctor, Dr Robinson, and he said I should stay at home until my stitches came out. I did have my stitches at Skimped Hill Health Centre Bracknell.

7. On 29 November 1983, [GRO-D] arrived to take my first blood tests. [GRO-D] was a nurse from Oxford who dealt with Haemophilia patients – she used to talk about them a lot. I had my stitches out on 5 December 1983. I was learning to swim around this time because of my asthma. [GRO-D] asked me one day what I had been doing and I told her I had been swimming. She then said I should not be doing that and I thought, “why not. It is only a blood test?” She said that I should not have been doing that and I should not have been feeling like I wanted to go swimming.
8. I had multiple blood tests. I have kept diaries for years and so I have some record of what went on. [GRO-D] came for a visit on 4 May 1984 for blood tests. On that day she told me that the results of a test taken on 28 March 1984 were not satisfactory and that if it continued then I would need to be admitted for further tests. [GRO-D] came again on 1 June 1984 for further tests. She gave no comment on tests done in May. I have not got a clue what they were doing these tests for, but they bloody well knew. I remember [GRO-D] saying to me one night that they ‘boiled all their blood’.
9. In October 1985, [GRO-D] rang and told me that they were doing tests for the possibility of AIDS. They continued giving me blood tests.
10. In October 1988, [GRO-D] arrived to give me an injection for Hepatitis B. I had an injection for Hepatitis B again in November 1988 and then another one in June 1989. In July 1991 I had a booster.
11. In 1993 we moved up to Norfolk and I changed doctors. My local GP was Dr Sampson of the Sherringham Medical Centre. It was November 1997 when I went to visit Dr Sampson, and it was that day that he told me that I had Hepatitis C through the Factor VIII I had received in November 1983. He said ‘you know you have got Hepatitis C don’t you?’ I laughed about it and he told me it was very

serious. He said it could kill me. I could see him thinking about it and eventually he sent me to Cromer Hospital to see Dr Kennedy, for further tests. I first saw Dr Kennedy on 24 February 1998 and he gave me a very thorough examination. Dr Sampson and I were very close as doctor and patient.

12. I had a scan at West Norwich in April 1998. That September, the results came back and Dr Kennedy told me the tests were all good, except the tests for HCV which were positive. Tests were also done for antibodies or something. Dr Kennedy was lovely. He used to treat all his patients and nurses the same. He was gorgeous.
13. On 20 February 2007 I mentioned I had a pain in my back so I went for a chest X-ray and also for tests to find out which type of HCV I had. I continued to have my blood tested and also I had scans to monitor my liver for psoriasis. In February 2008 my medical records confirm that I was GENO Type 4R, which is apparently very rare.
14. I did not know how I had to manage the infection. Dr Kennedy used to talk a lot but I think he could have explained it more really. As far as my knowledge goes, my memory is blank as to the information I was given to understand the infection.
15. I do know that between 1983 and 1993 I was somehow aware that I had to be careful around the children. During this time I was helping to look after two toddlers because my son was going through a divorce. [GRO-D] had told me I had to wear rubber gloves if the children needed piasters for grazed knees and so on. But I was never told why exactly. I had asked [GRO-D] at one visit what was I being tested for and she told me 'everything.' She pointed to the moon and said 'if that moon was made of cheese, I would be worried. But it is not and I am not'. Simply being advised to wear rubber gloves was of no comfort to myself, my husband or my family. Also, I do not know why [GRO-D] was telling me back then to wear gloves. I had not been told of my infection then.

16. I am happy with how I was told. I can imagine that Dr Sampson looked through my notes. He was the first doctor we had up here in Norfolk, and I did not mention it to him because I did not know myself.

Section 3. Other Infections

17. I do not believe I have received any infection or infections other than HCV as a result of being given contaminated blood products.

Section 4. Consent

18. I have been treated with my knowledge and consent. But they would come for blood tests saying that they were testing for jaundice. I have never been treated for any jaundice.

Section 5. Impact

19. I did not receive treatment for my HCV infection. Dr Kennedy said that the treatment was so horrible. Perhaps I was given the offer but I cannot remember. My husband remembers it was explained to me and that I said I did not want it. I do not think Dr Kennedy mentioned the names of the treatment, but he did explain what it was like. He said we would see how we go because I was doing fine. I said ok and that is what we did. I have not suffered through not having it.
20. Dr Kennedy wanted to do a biopsy of my liver but dared not because of my Von Willebrand's. I have still got HCV but it is ok. When Dr Kennedy retired, the various tests dwindled right down. I do not think my liver has deteriorated any more, though I am monitored annually.
21. I have suffered from Chronic Fatigue since January 2015, as noted from Dr Sampson on my Special Category Mechanism (SCM) application form to the England Infected Blood Support Scheme (EIBSS). Dr Sampson has been seeing me for this. I have been

feeling extremely tired for many years now with some of the family saying that I am always tired in a sarcastic way which makes me think that they think I am just putting it on.

22. It affects me most days and every week. I try to keep a daily routine but forget now what I am supposed to be doing and have to stop and start again. Sometimes I leave the cleaner running or washing machine on without anything in it. Then I start doing something totally different. It also affects me while shopping as I arrive home without items we require or the shop assistant will run after me to say I have forgotten something. It is getting worse over the years. That worries me. I have become very tired and depressed.

23. I always walked to Sherringham to shop. About a mile I guess. Now it is the bus and getting to the stop and waiting is an effort, especially in the cold weather. Taxis are another choice but they are expensive for some journeys. Many drivers remain in the cars so no help is given and it makes me feel anxious and exhausted. We have our general grocery shopping delivered. One store generally leaves the bags just inside the front door. The other brings the bags into the kitchen in containers. I then have to pick the goods up onto to the work surface to put away as the containers have to go back. Sometimes the drivers will help but not always, and I cannot expect them to.

24. Over the last two or three years, every job I do in the house is an effort. I love cooking but making pastry now makes me out of breath and I need a rest. It just seems there is always something against me, which is so depressing. I am just so tired.

25. When I was informed about my HCV infection, we were worried about the grandchildren possibly having been infected. GRO-C
GRO-C My social life did not really change and GRO-C with my husband waivered off with age. I used to be a professional ballroom dancer and I was able to

keep dancing for as long as any person could have done. I only stopped 6 years ago.

26. I do not ever recall being treated differently in any way because of my HCV infection. I have been lucky, I really have. That is why I am doing this, because of the people that died and left kids behind. I have coped all my life with the side effects. I was able to keep dancing. However, it has upset my life because it has always been there.

Section 6. Treatment/Care/Support

27. As explained above, I did not receive treatment for my HCV. Counselling or psychological support has not been made available to me as far as I can remember.

Section 7. Financial Assistance

28. I found out what financial assistance was available because of Dr Kennedy. I went in and he said that we could try and get some financial assistance. We did it in the surgery at Cromer Hospital. We filled in an application form together and Dr Kennedy signed it. That was the application for Skipton and it seemed an easy enough thing to do.
29. I have received numerous payments from the Skipton Fund and from Caxton. I received £20,000 in September 2004 from Skipton as well as two payments of £3,500 each in 2015 and 2016. From 2017 I began to receive quarterly payments of about £750-780.
30. Since about 2015 I have been receiving monthly payments from Caxton in the region of about £208. I was given a winter fuel allowance of £500 in December 2015, and again in December 2017 in the sum of £505.

31. These payments have since been taken over by EIBSS. My monthly payments of £208 have continued until now. However, this year I also received following payments: £6,060 in March and four payments of £4,500 in March, April, July and October. A few other payments have been made to me here and there, including £817.50 in January 2018, a few instalments of £362 and £881 has just arrived this November.
32. I think the financial assistance I have received has been fair, but I do think there are other people who need it more. There are also people who will probably try for it, who do not really need it. I have accepted what they have given me and I have kept it for a reason, in case anything happens to my health. I am worried about my liver. The HCV has impacted me because I have put all the money I have received from them away, when I could be spending it on other things.
33. I do think other people, such as mothers, fathers, and children who have had to struggle on after their loved ones died, deserve that money more.

Section 8. Other Issues

34. Somebody at Oxford must have known I was infected with Hepatitis C, and also at Bracknell. It must have gone from the GP in Oxford to Bracknell, and then from Bracknell to here (Sherringham), because Dr Sampson knew. I want to know why it happened and how it was allowed to happen. Why is it that all these people came to be infected by contaminated blood and who is to blame? If we do not know, it will happen again. Maybe not the same thing exactly, but it will happen again.
35. I have been asked if I am legally represented on this matter and I confirm that I am not.

36. I have not personally campaigned on the subject of infected blood. However, as part of the contaminated blood campaign backed by the Haemophilia Society, I wrote a letter to my local MP, Norman Lamb, asking him for support regarding compensation for patients that have been infected with HCV and HIV as a result of receiving contaminated blood. On 26 November 2009, I received a reply from Norman Lamb. An extract from his reply reads 'I fully support the case for compensation and I would be happy to sign an Early Day Motion on the subject if it is tabled in the current sessions.'
37. Having now spoken with 'The Inquiry' I am now going to make efforts to recover all of my medical notes which may help me understand my story more comprehensively.

Statement of Truth

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

Signed

GRO-C

Dated

18th December 2018